

Open Research Online

The Open University's repository of research publications and other research outputs

The significance of social support and close relationships for people with learning disabilities

Thesis

How to cite:

Lippold, Tessa (2000). The significance of social support and close relationships for people with learning disabilities. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2000 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e2ce>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

TESSA LIPPOLD BA Hons Dip Clin Psych

**THE SIGNIFICANCE OF SOCIAL SUPPORT AND CLOSE
RELATIONSHIPS FOR PEOPLE WITH LEARNING
DISABILITIES.**

A thesis submitted in partial fulfilment of the requirements of the Open University
for the degree of Doctor of Clinical Psychology

NOVEMBER 2000

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE

ACKNOWLEDGEMENTS

First and foremost I would like to thank my supervisor, Dr Jan Burns, for her advice and wisdom, clear thinking and belief in me.

Secondly I would like to thank all the participants who gave their time so willingly, and all the day centre managers who were prepared to make the arrangements and initial introductions.

I would also like to thank Tom Chan for help with ethical committees and Sue Holttum for statistical advice.

Especial thanks are due to Yona Lunskey for sharing her own research so generously and for her prompt e-mail responses.

Thanks too to the rest of Cohort 2 who lasted the distance, in particular thanks to Hedy for her support in the final few weeks. Last, and by no means least, I must thank my own innermost circle of support – Tony and the children – for all their help and tolerance over the last year or so.

ABSTRACT

Background and aims

The social and personal relationships of people with learning disabilities were explored, including the characteristics of their social networks, the extent of social integration and the availability of social support. It was hypothesised that people with learning disabilities would be less socially integrated, have more restricted social networks and more limited social support than a comparison group of people with physical disabilities.

Design and participants

A mixed methodology was employed. In the first part of the study participants were 30 people with learning disabilities, a nominated carer for each of the 30 participants and a comparison group of 17 people with physical disabilities. The second part of the investigation consisted of semi-structured interviews with 6 of the people with learning disabilities.

Measures

Measures used included the Life Experiences Checklist, the Circles task, the Social Support Self Report, the Functional Support Inventory and the Social Circles Questionnaire. The author devised a semi-structured interview to assess understanding of different kinds of relationships. Transcripts were analysed using content analysis.

Results

Levels of integration were better than expected in all areas apart from relationships. Participants reported a mean social network size of 11.7, significantly lower than the comparison group. The networks of people with learning disabilities were largely composed of family or friends with learning disabilities whereas non-disabled friends made up the majority of the network for the comparison group. There were few differences between the groups in terms of perceived social support. Themes identified from the interview data included the provision of emotional support by friends and betrayal of trust in romantic relationships.

Implications

The findings indicate that people with learning disabilities may be functionally but not fully socially integrated within the community, thereby lacking opportunities to experience a wide range of relationships. Directions for future research are suggested.

CONTENTS

| | |
|--|--------|
| 1 INTRODUCTION | 1 |
| 1.1 Friendship | 2 |
| 1.2 Friendship formation..... | 3 |
| 1.3 Friendship and learning disabilities | 5 |
| 1.4 Facilitation of friendship between people with and without disabilities . | 7 |
| 1.5 Social integration of people with learning disabilities | 8 |
| 1.6 Social support: some definitions..... | 9 |
| 1.7 The buffer theory of social support..... | 10 |
| 1.8 Social support: the sense of acceptance and the role of relationships | 11 |
| 1.9 The convoy model..... | 12 |
| 1.10 Social support and learning disabilities | 13 |
| 1.11 Social support and psychopathology in people with learning disabilities..... | 16 |
| 1.12 The impact of disability..... | 17 |
| 1.13 Focus of the research..... | 18 |
| 1.14 Methodological issues | 19 |
| 1.15 Aims of the research | 21 |
| 2 METHODOLOGY..... | 23 |
| 2.1 Design | 23 |
| 2.2 Ethical Approval | 24 |
| 2.3 Participants | 24 |
| 2.3.1 Learning disability group..... | 25 |
| 2.3.2 Physical disability group | 25 |
| 2.3.3 Informant group | 26 |
| 2.4 Recruitment..... | 27 |
| 2.5 Measures | 27 |
| 2.5.1 The Social Support Self-Report (SSSR)..... | 29 |
| 2.5.2 The Circles Task..... | 30 |
| 2.5.3 The Functional Support Interview (FSI) | 31 |
| 2.5.4 The Social Circles Questionnaire (SCQ) | 32 |
| 2.5.5 The Life Experiences Checklist (LEC) | 34 |
| 2.5.6 Semi-structured interview schedule..... | 35 |
| 2.6 Qualitative methodology..... | 36 |
| 2.7 Procedure..... | 38 |
| 2.7.1 Piloting | 38 |
| 2.7.2 Procedure for first Interview..... | 40 |
| 2.7.3 Informed Consent | 40 |
| 2.7.4 Completion of measures..... | 42 |
| 2.7.5 Procedure for second interview | 42 |

| | |
|--|----|
| 3 RESULTS | 44 |
| 3.1 Demographics | 44 |
| 3.2 Consent..... | 48 |
| 3.3 Acquiescence..... | 49 |
| 3.4 Statistical Analysis..... | 50 |
| 3.5 Research Question 1..... | 50 |
| 3.5.1 Social integration | 50 |
| 3.5.2 Social networks..... | 52 |
| 3.5.3 Social support..... | 54 |
| 3.6 Hypothesis | 58 |
| 3.6.1 Social integration | 58 |
| 3.6.2 Social networks..... | 59 |
| 3.6.3 Social support..... | 61 |
| 3.6.4 Impact of living arrangement | 63 |
| 3.7 Research Questions 2 and 3..... | 63 |
| 3.8 Key results | 70 |
| 4 DISCUSSION..... | 72 |
| 4.1 Review of methodology..... | 72 |
| 4.1.1 Recruitment | 72 |
| 4.1.2 Procedure and measures | 73 |
| 4.2 Discussion of results | 76 |
| 4.2.1 Social integration | 76 |
| 4.2.2 Social networks: size | 79 |
| 4.2.3 Social networks: composition | 81 |
| 4.2.4 Social support: self-rated | 81 |
| 4.2.5 Social support: informant-rated..... | 83 |
| 4.2.6 Understanding of relationships | 86 |
| 4.3 Implications of the research | 89 |
| 4.3.1 Implications for clinical practice | 89 |
| 4.3.2 Implications for future research | 91 |
| 4.4 Conclusion | 92 |

LIST OF TABLES

| | | |
|-----------|--|----|
| Table 1. | A summary of measures used..... | 28 |
| Figure 1. | Age distribution of participants..... | 45 |
| Figure 2. | Living arrangement of participants..... | 46 |
| Table 2. | Questions asked to determine ability to consent..... | 49 |
| Table 3. | Questions asked to assess acquiescence. | 49 |
| Table 4. | Scores obtained on the Life Experiences Checklist (n=30)..... | 51 |
| Table 5. | LEC: comparison with general population..... | 51 |
| Table 6. | LEC: comparison with learning disability sample. | 52 |
| Table 7. | Composition of support network..... | 54 |
| Table 8. | Means and SDs for ratings by support source (self-rated). | 55 |
| Table 9. | SSSR one-sample t-tests..... | 56 |
| Table 10. | Means and SDs for ratings by support source (informant rated)...57 | |
| Table 11. | SCQ one-sample t-tests..... | 57 |
| Table 12. | Scores obtained on the LEC, physical disability group, n=17 | 59 |
| Table 13. | LEC: comparison between LD group (n=30) and PD group (n=17)..... | 59 |
| Table 14. | Comparison of network size, LD and PD groups. | 60 |
| Table 15. | Comparison of network members, LD and PD groups (Mann-Whitney)..... | 61 |
| Table 16. | FSI: comparison between PD and LD groups (Mann-Whitney)..... | 62 |
| Table 17. | SSSR: comparison between PD and LD groups (Mann-Whitney)..... | 62 |
| Table 18. | Characteristics of sub-group. | 64 |
| Table 19. | Themes relating to friendship..... | 65 |
| Table 20. | Themes relating to romantic relationship. | 66 |
| Table 21. | Themes relating to intimate relationships..... | 67 |
| Table 22. | Themes relating to relationships with staff. | 68 |
| Table 23. | Themes relating to negative impact of relationships. | 69 |

LIST OF APPENDICES

| | |
|-------------|-------------------------------------|
| Appendix 1 | Ethical approval |
| Appendix 2 | Information sheets and letter to GP |
| Appendix 3 | Consent forms |
| Appendix 4 | Social Support Self Report |
| Appendix 5 | Circles task |
| Appendix 6 | Functional Support Interview |
| Appendix 7 | Social Circles Questionnaire |
| Appendix 8 | Life Experiences Checklist |
| Appendix 9 | Semi- structured interview schedule |
| Appendix 10 | Sample of transcript |
| Appendix 11 | Outline transcript |

1 INTRODUCTION

One of the defining characteristics of human beings is the ability to be social. Most people choose to live, work and play with other people and most of our lives are spent interacting with others. The need to develop and maintain relationships with other people is fundamental to normal psychological development and well-being. Personal and social relationships range from the formal or impersonal to the intimacy of lovers. They include family ties, about which there is little choice, but which can last a lifetime, as well as brief encounters, acquaintances and friendships, which can involve choice. Clearly relationships can vary in quality and intensity and also in terms of ascribed importance.

People with learning disabilities may have fewer opportunities to develop a full range of social and personal relationships and may, by definition, have a more limited grasp of social skills (Flynn, 1989). Following the closure of most of the large institutions and the widespread adoption of the principles of Normalisation (Wolfensberger, 1972), considerable changes have occurred in the way many people with learning disabilities live. However community presence has not necessarily been accompanied by social integration and evidence suggests that for many people with learning disabilities friendships and close relationships remain elusive (Myers, Ager, Kerr & Myles, 1998).

The aim of the present research is to explore the nature of social networks, close relationships and social support experienced by people with learning

disabilities. A comparison will be made with people with other kinds of disabilities who share some of the same lifestyle characteristics, such as lack of paid employment and dependence on others, with a view to establishing the impact of learning disability as opposed to disability. In order to place the social lives of people with disabilities in context, the literature on the social psychology of friendship and friendship formation will be reviewed, with particular attention being paid to people with learning disabilities. This will be followed by reviews of the development of the concept of social support and of research into the importance of social networks and social support for people with learning disabilities

1.1 Friendship

Definitions of friendship typically include the notion of a reciprocal relationship with mutual benefits, mutual liking and mutual enjoyment (Bukowski, Newcomb & Hartup, 1996). The idea of a friendship being a voluntary relationship is also important (Wright, 1984). Each friendship may be unique and the people who are friends will have their own perspectives on their relationship (Luttfiya, 1991). Another important factor is that friendships have a longitudinal perspective and develop over time. Friendship may be experienced differently at different times and under different circumstances (Duck, 1990), which can make it a difficult concept to measure objectively. Hazan & Shaver (1987) proposed that Bowlby's (1971) theories on mother-child attachment could provide a useful framework for understanding intimate relationships in adulthood. G.McCarthy (1999) further developed these ideas

and found that women with secure attachment styles had significantly more positive ratings in the domains of adult love relationships and friendships than women with avoidant or ambivalent attachment styles.

1.2 Friendship formation

Early theorists conceptualized interaction in terms of exchange processes (Homans, 1961; Thibaut & Kelley, 1959). Social exchange theory focuses on the relation between individuals rather than on individuals themselves, and on process rather than structural aspects of a relationship. The emphasis is on how this process changes as a result of reciprocal reinforcement. The concepts of reward, cost, outcome and comparison level are key to exchange theory. Any activity on the part of one person that contributes to the gratification of another person's needs is considered a reward. Costs refer not only to "punishment" incurred in engaging in an activity, such as fear of embarrassment, but also the value of rewards that the person decides to forgo in engaging in one interaction rather than another (Homans, 1961). The reward-cost outcome must be above a minimum level of expectation, the comparison level, for attraction to occur. This comparison level is influenced by past experiences in the relationship and in comparable relationships, and perceptions of alternative relationships (Secord & Backman, 1974).

A wide range of variables has been found to be important in determining how friendships are formed and maintained over time. These include age, gender, socioeconomic status and physical proximity. Other less observable variables

include sharing of perceptions and interests. Research on similarity and attraction has shown that people are more strongly attracted to those who share their attitudes and the greater the proportion of shared attitudes, the greater the attraction: The critical similarities are those concerning beliefs, attitudes and values (Cramer, 1998)

The idea of complementarity in a partnership was introduced by Winch (1958). Although not denying that people who form close relationships are often similar in many respects such as social background, Winch (1958) found a tendency for married partners to have complementary needs. Thus a person with a strong need to nurture has a partner who has a strong need to be nurtured. More recently researchers have argued that complementarity develops during a relationship and involves resources such as physical beauty and money (Rubin, 1973).

There is considerable evidence to support the general view that physical attractiveness has an important influence on initial impression. Attractive-looking people may have a "head start" in the early phase of relationship development. Compared to unattractive people they are in general perceived as happier, more popular, successful and more socially skilled. They are also assumed to be higher in traits such as intelligence (Feingold, 1992).

Definitions of physical attractiveness tend to be subjective and are evidently culturally and historically determined. However Langlois & Roggman (1990) found that generally "attractive" facial and bodily features do not deviate too

much from the average. They used computer technology to produce digitised images whose features could be altered to be nearer or further away from the “average”. The perfectly average image was rated as strikingly attractive.

A criticism of much of the research in social relationships is that it has tended to focus on dyadic attraction at the point of interaction. Duck (1995) argued that the quality and validity of data should be questioned as many studies use college students or strangers, and are based on photographs. Early studies rarely looked beyond immediate judgements of attractiveness or expressions of readiness to see somebody again. The effect of physical attractiveness is therefore more likely to be limited to influencing the range of people who regard themselves as available to us (and vice versa) but “it is personality and attitudes that account for success, stability, companionship and depth in relationships” (Duck, 1999, p.30). Longitudinal studies that address factors such as stability of social relationships reflect more recent approaches to the area (Duck & Miell, 1986).

1.3 Friendship and learning disabilities

For people with learning disabilities it has been argued that friendships may make the difference between integration and isolation within a community (Barber & Hupp, 1993). The influence of Normalisation (Wolfensberger, 1972) on the provision of services has meant that people with learning disabilities are increasingly living among, working and interacting with people without disabilities. Friendship between adults with and without disabilities is

perceived as the next step to aim for and perhaps a crucial factor in ensuring a successful transition to integration (Green, Schleien, Mactavish & Benepe, 1995; Kennedy, Horner & Newton, 1989). In their review of studies of social and community integration Myers et al (1998) concluded that physical presence was insufficient of itself to achieve integration in a community and that “people with learning disabilities often remain, socially, outside looking in” (Myers et al, 1998, p.393).

Much of the work on friendship in people with learning disabilities has addressed the friendships between those with and without disabilities (Lutfiyya, 1991; Newton, Olson & Horner, 1995; Taylor & Bogdan, 1989). Such friendships can and do exist (Lutfiyya, 1991; Taylor & Bogdan, 1989) and often emerge out of an earlier professional or caring relationship, developing once the person without a disability moves to a different context (Newton et al, 1995). A process of “de-labelling” may need to occur before the stigma and negative characteristics associated with disability and difference are overcome and the person is accepted as a friend on more equal terms (Taylor & Bogdan, 1989).

Others have argued that close friendship between people with and without learning disabilities is not that common. Green & Schleien (1991, cited in Green et al 1995) suggested that the occurrence of such friendships might be overestimated because of false perceptions whereby “facades of friendship” are taken as “true friend” experiences. Friendly overtures and increased

social contact are misinterpreted by both clients and care providers as constituting friendship. Many people with learning disabilities who report having a friend in fact experience a relatively superficial relationship more akin to that of an acquaintance (Clegg & Standen, 1991).

1.4 Facilitation of friendship between people with and without disabilities

Mothers of children with disabilities actively facilitate friendships between their children and peers without a disability by finding opportunities and exposing them to a wide range of potential friends (Turnbull, Pereira & Blue-Banning, 1999). Once people with learning disabilities are living in residential settings they are more likely to depend on others in the same setting for friendship than to branch out to the wider community (Barber & Hupp, 1993). Newton et al (1995) suggested that, with the right encouragement, relationships between people with learning disabilities and care staff can develop into long term friendships that flourish once the professional barrier is removed. Other researchers have looked at friendships that have been more contrived, for example, by setting up social partnerships between college students and a same-age partner with a learning disability (Green et al, 1995). At first participants were open-minded about developing social relationships with peers with learning disabilities but faced barriers because of preconceived ideas and beliefs that such people were physically, emotionally, behaviourally and socially different. The process of delabelling described earlier (Taylor & Bogdan, 1989) appeared to operate initially in that participants expressed

feelings of pleasant surprise that their partners were not so different after all once they had begun to get to know each other. However there was little evidence of relationships being sustained beyond the first six weeks of the study.

Encouraging relationships between people with and without disabilities is not universally accepted as an ideal. Chappell (1994) argued that there is an assumption in much of the literature that friendships between disabled and nondisabled people are far preferable to those between disabled people.

According low values to relationships between people with disabilities risks damaging individual self-esteem and fails to give any positive messages to people with learning disabilities about some of the benefits of mixing with people with whom one shares important experiences (Chappell, 1994).

1.5 Social integration of people with learning disabilities

Although Taylor & Bogdan (1989) were able to give examples of successful and meaningful friendships between people with severe disabilities and community members, they added the caveat that many of the people they had studied were isolated and cut off from the wider community. A network of caring community members did not surround most people with a learning disability. Flynn (1989) similarly concluded that although most of her sample of people with learning disabilities living in their own homes had regular contact with individuals who could be described as friends, some experienced loneliness and isolation and some people's networks were found wanting.

The literature on friendship and learning disability therefore highlights issues such as paucity of friends and difficulties with achieving full social integration. There are fewer examples of studies that address friendship formation and the development and maintenance of stable relationships over time.

1.6 Social support: some definitions

The size and structure of an individual's social network and the nature of available social support are important aspects of social relationships. The extent to which a person receives the type and amount of social support that is needed or desired may be one indicator of the quality of their social relationships (Gottlieb, 1983).

Social networks and social support are related but distinct concepts. Social networks can be defined as the structure of identified social relationships that surround an individual, its characteristics and connections (Bowling, 1997). Network assessments have been concerned with properties such as size, density, homogeneity, degree of reciprocity between network members and the direction of linkages and interaction (Flaherty, Gaviria & Pathak, 1983).

Social support can be defined in terms of the availability of people whom the individual trusts, on whom they can rely and who make them feel cared for and valued as a person (McDowell & Newell, 1996). According to Alloway & Bebbington (1987) the concept of social support has been influenced by

Durkheim's development of the idea of anomie (trans.1951), Cooley's concept of the Primary Group (1909) and Bowlby's ideas on attachment (1971). Social support may have multiple functions and roles. For example, social support may be seen in terms of its function at both an individual level and for wider society, it can be analysed in terms of other people's behaviour towards a person and also in terms of a person's behaviour towards others when seeking support (Alloway & Bebbington, 1987). It may encompass both practical help and emotional support. Kahn & Antonucci (1980) conceptualised social support as a triad of aid (helping and advising), affirmation (someone saying they are of like mind) and affect (someone saying they like you).

1.7 The buffer theory of social support

In recent years social support has attracted interest in a number of areas including psychiatric disorders (Alloway & Bebbington, 1987), older adults (Antonucci & Akiyama, 1987), health-related behaviour (Broman, 1993), physical disabilities (McColl & Skinner, 1995) and learning disabilities (Newton, Horner, Ard, LeBaron & Sappington, 1994). In psychiatry research has focused on the perceived supportiveness of relationships and has sought to confirm the buffer theory of social support (Cohen & Wills, 1985). The buffer theory holds that social support acts as an intermediary variable in moderating the potentially negative effects of stress. The findings of Brown & Harris (1978) that depression in the face of life events or chronic difficulties is more likely when a close, confiding relationship is lacking give rise to a

concept which is equivalent to buffering but in the inverse sense i.e. the absence of social support makes a person vulnerable to stress and having social support buffers the effect of stress (Bolton & Oatley, 1987).

Despite initial enthusiasm for the buffer effect research has produced inconsistent results (Alloway & Bebbington, 1987; Lin, Woelfel & Light, 1986), some of which may be due to conceptual difficulties and methodological shortcomings such as the use of measures with doubtful psychometric properties (Bowling, 1997). The debate amongst researchers has been whether the benefits of social support are obtained via a buffering or direct effect on health or stress (Alloway & Bebbington, 1987; Cohen & Wills, 1985). There is no doubt that a relationship does exist between social support and mental and physical well-being and as Newton et al (1994) argued the weight of evidence supports the view that social relationships are indeed protective of health.

Two theoretical models, both of which adopt an interactional perspective, go some way toward clarifying some of the complexities involved in the area.

1.8 Social support: the sense of acceptance and the role of relationships

Arguing from the standpoint that social support as a concept is all-encompassing, Sarason, Pierce & Sarason (1990) developed a theoretical model which divides it into several parts: (1) a sense of acceptance, (2)

perceived available support, (3) the support that is received from others, and (4) the recipients' perceptions of that support and their satisfaction with it. The model also includes the primary relationships, both early and current, which are believed to be important for understanding the effects of supportive behaviour.

1.9 The convoy model

Antonucci & Akiyama (1987) proposed a theoretical framework of interpersonal relationships over time, known as the convoy model of social support. The term "convoy", which is borrowed from anthropology, refers to a protective layer of family and friends who surround the individual and help them negotiate life's challenges. Convoys are viewed as dynamic and lifelong in nature and whilst they remain stable in many ways, they are also changing over time. Thus family members typically remain an important part of one's support network throughout one's life, but the nature of such relationships changes over time with aging and experience.

Kahn & Antonucci (1980) presented a method of visualising the convoy as a set of three concentric circles that surround the person. The innermost circle contains the individuals who are perceived as the most important support providers and support recipients and are those to whom the identified person feels closest. The relationships in the inner circle are relatively stable; they transcend role requirements and include the exchange of many different types of support (Antonucci & Akiyama, 1987). Members of the second circle

are not as close although again relationships typically are about more than fulfilling role requirements. The outer circle is characterised by relationships that are still close but very role prescribed (as in the case of colleagues who have an important and close relationship but only within the work environment).

1.10 Social support and learning disabilities

Recently there has been a developing research interest in social networks and social support among people in disadvantaged groups. It has been argued that one reason for this interest lies in the fact that informal sources of support and help for disadvantaged people have become increasingly recognised by politicians and policy makers as a resource worth tapping (Grant, 1993). The American Association on Mental Retardation's current definition of "mental retardation" (i.e. learning disability) (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik & Stark, 1992), includes the concept of support.¹ This definition has contributed to an increase in research

¹ Mental retardation is characterised by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, work. Mental retardation manifests before age 18. The following four assumptions must be considered when applying the definition: valid assessment considers cultural and linguistic diversity, as well as differences in communications and behavioural factors; the existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports; specific adaptive limitations often co-exist with strengths in other adaptive skills or other personal capabilities; with appropriate supports over a sustained period, the life functioning of a person with mental retardation will generally improve.

into social support and its measurement in the United States (Lunsky & Benson, 1999).

According to Rosen & Burchard (1990), before their own study, there had been no attempts to determine how the social support systems of adults with a learning disability compared to those of similar individuals without disabilities living in similar communities. Rosen & Burchard (1990) compared the social support networks, community-based activities and personal well-being of a group of 27 adults with learning disabilities living in semi-independent apartments with those of a group of adults without learning disabilities matched for age, gender, marital status and community size. The social networks of the adults with learning disabilities were found to be smaller, contained proportionately fewer friends, had less reciprocity and contained a large proportion of service providers. Over half of the participants with disabilities named a member of staff as their most frequent source of companionship and support. There were no differences between the groups in either perceived supportiveness or satisfaction with contact with network members. The research highlighted the limited social integration of adults living in supervised apartments, who are amongst the most skilled and independent of all people with learning disabilities.

The emphasis on social integration in relation to community living has meant that much of the research has focused on people with disabilities who live either independently (Edgerton, 1967; Flynn, 1989) or in supervised or staffed

housing (Rosen & Burchard, 1990; Dagnan & Ruddick, 1997). Less research has been conducted into the social support of adults with learning disabilities who live with or under the supervision of their families. In one of the few studies to address the situation of families caring for an adult with a learning disability, Krauss, Seltzer & Goodman (1992) found an average network size of 7.1 with considerable variability. According to data collected solely from the mothers almost three-quarters of the network members of the 462 adults with learning disabilities were family members. Most of the support identified was provided to the adult with a learning disability and very little was reciprocated. The networks were described as deeply embedded with the social support networks of their mothers. Two groups were identified as at particular risk: men with learning disabilities, who had a lower percentage of friends and fewer same-sex friends than women, and individuals with severe learning disabilities, who had the smallest networks and were most likely to have no friends.

In their study of adults with a learning disability over the age of 40 living with relatives in the family home Prosser & Moss (1996) found that the structure and functioning of the support networks operated on a hierarchical basis. The majority of the networks were sustained by the main carers (principally parents) with little shared support from either other family members or from the wider community of friends and neighbours. Of particular concern were those increasingly elderly carers who themselves lacked an appropriate support network. Similar concerns were raised by Grant (1993) who found

that informal support in the community was all too often limited to maternal care and that for many mothers:

Their commitment shades into stoicism, a reluctance to share responsibility, and often a refusal to transfer the substantive responsibility for support to other network members in the face of growing personal incapacity. (Grant, 1993, p.51)

1.11 Social support and psychopathology in people with learning disabilities

Other studies that have more directly addressed the deleterious effects of low levels of social support for people with learning disabilities have been concerned with outcome measures of psychological health. Associations have been reported between low levels of social support and depression in people with mild learning disabilities (Reiss & Benson, 1985; Meins, 1993; Nezu, Nezu, Rothenberg, DelliCarpini & Groag, 1995). Meins (1993) argued that since people with learning disabilities are particularly dependent on the support of others it would be reasonable to assume that inadequate social support has a worse effect on them than on members of the general population. Lunsky & Haverkamp (1999) extended the work of Nezu et al (1995) by measuring several types of psychopathology in addition to depression and including individuals with the full range of learning disabilities. They used an informant rating scale, the Social Circles Questionnaire, which assessed both social support and its converse, social strain. The presence of

social strain was more strongly associated with rated psychopathology than was the absence of social support. The findings would appear to fit the argument proposed by Coyne & Downey (1991) that rather than focusing solely on social interactions that convey support, researchers should also emphasise the factors that reduce the sense of support, such as conflict, inhibited communication and lack of stability in close relationships.

Newton et al (1994) offered a conceptual framework for describing a person's social life. Arguing from the standpoint that social relationships could be the most essential elements and indicators of societal inclusion, they described a person's social life in terms of four variables: their personal or social network, social interactions, social stability and social support. The first three of these variables may be independent variables which serve to influence the amount and type of social support that an individual is able to acquire (Newton et al, 1994). Such a framework has implications for the assessment of social support needs of people with learning disabilities and for subsequent interventions.

1.12 The impact of disability

The importance of social support to people with physical disabilities has long been recognised (McColl & Skinner 1995). However much of the literature in the area has been limited to anecdotal accounts of the importance of the spouse and immediate family and has seldom extended beyond the period of inpatient rehabilitation (McColl & Skinner, 1995). Support for the buffering hypothesis of social support was found in a cross-sectional study of 1100

community-based individuals with self-reported disability (Patrick, Morgan, & Charlton, 1986, cited in McColl & Skinner, 1995).

Other research into the quality of life of people with and without disabilities found differences between the two groups across a wide range of dimensions including the extent of social networks, opportunities to make choices and activities experienced (Sands & Kozleski, 1994). The group with disabilities in this study was a mixed group that included almost 40 percent whose primary disability was not a learning disability. However it could be argued that not all kinds of disability have a similarly negative impact on the ability to develop social networks and benefit from social support. Including both physical and learning disabilities in the same group risks the disadvantages of overgeneralization and negatively valued stereotypes (Harris, 1995). Overall there appears to be a dearth of literature which compares the experiences of different disadvantaged groups.

In order to establish whether it is disability *per se* or learning disability in particular that is significant, it is worth comparing the social networks and support available to people with different kinds of disabilities, for example, learning disabilities and physical disabilities.

1.13 Focus of the research

Much of the work on social support and learning disabilities has been undertaken in the United States with people with mild learning disabilities

living in residential care. For the most part, the participants are the care staff, who act as informants for the person with a learning disability (one notable exception is the work on self-report measures of social support conducted by Lunsky & Benson, 1997). Moreover, recent advances in conceptualising social support have not always been considered in studies where the focus is on learning disabilities. The present study aims to add to the understanding of social networks and social support of people with disabilities and will not rely solely on the views of the carers but will involve people with learning and physical disabilities as active participants. The views of people with learning disabilities on friendship and other kinds of relationships will also be sought.

1.14 Methodological issues

There are difficulties in measuring social support and social networks because of lack of agreement on conceptual bases and limited testing of validity and reliability of measures (Bowling, 1997). In her review of measures of social support and social networks, Bowling (1997) highlighted difficulties with reliability including the lack of stability of measures. She also identified the problem of over-reliance on subjective perceptions, particularly in situations where a respondent is feeling depressed and perceives their available support to be inadequate when objective evidence would suggest the contrary. Bowling (1997) proposed carrying out additional interviews with others in the same network to verify the information supplied by the respondent. In learning disabilities the opposite problem is likely to arise because of an over-reliance on information obtained from others (such as

care staff), thereby running the risk of ignoring a vital source of information (Prosser & Bromley, 1998). However some authors have demonstrated that it is possible to use self-report measures, provided they are appropriately adapted, with people with learning disabilities. Rosen & Burchard (1990) emphasised in their study the importance of obtaining the information from the individuals themselves wherever possible. Others have argued for a multi-method approach (Parker, Sprague, Flannery, Niess & Zumwait, 1991). Lunskey & Benson (1997) addressed the issue of reliability in their study of adults with mild learning disabilities and their staff in residential settings. Participants and care staff completed a variety of self-report and informant measures of social support. Results confirmed that people with learning disabilities could be reliable self-reporters.

Interviewing people with learning disabilities does present certain challenges for the researcher. On the one hand it is recognised that people with learning disabilities should become more active participants in research (Kiernan, 1999; Rodgers, 1999) on the other lie the pitfalls of acquiescence and “yea-saying” noted by Sigelman, Budd, Spanhel & Schoenock (1981). In a detailed review of the issues, Finlay & Lyons (2000) concluded that apparent acquiescence could occur for a number of reasons other than the participant wanting to agree with the interviewer. These reasons include that it is a response strategy for when the answer is unknown, that the person is saying “yes” to indicate they have understood the question and that it might arise when question structures are too complex. In the latter situation respondents

may focus only on some of the words in the question or on words in their root form, such as “happy” instead of the given “happier”.

The use of questionnaires with a fixed-response schedule also presents difficulties. Antaki & Rapley (1996) used the qualitative approach of conversation analysis to show that not only are questions modified to ensure they are understood but also answers are frequently distorted by interviewers of people with learning disabilities to fit pre-determined categories. The use of an open-ended question format might also be assumed to be problematic because of lack of responsiveness, however a number of researchers have successfully used this method (Booth & Booth, 1994; M. McCarthy, 1999). The way forward may be to use appropriately valid and reliable measures where these exist in combination with more qualitative methods that can more directly canvas the views of the individuals concerned. This mixed methodology was adopted in the study to be reported.

1.15 Aims of the research

The aim of the present study was to explore aspects of social relationships, specifically, social support, networks and integration, in people with disabilities. The main focus of the research was on people with learning disabilities but comparison data were obtained from a group of people with physical disabilities in order to clarify the impact of a learning disability. The following research questions and hypothesis were posed:

Research Questions:

1. What are the characteristics of social integration (as measured by the Life Experiences Checklist) social networks (as measured by the Circles technique), and social support (as measured by the Social Support Self Report, the Functional Support Inventory and the Social Circles Questionnaire) among people with learning disabilities?
2. What do people with learning disabilities think about the social networks and social support available to them?
3. What is the understanding of people with learning disabilities of different relationships, such as friendship and close personal relationships, and what meaning do they ascribe to their experience of such relationships?

Hypothesis:

- People with learning disabilities will have lower levels of social integration, more restricted social networks, and fewer sources of social support than a comparison group of people with physical disabilities.

2 METHODOLOGY

2.1 Design

The design reflected the exploratory nature of the study. Both quantitative and qualitative methods were employed. The first part of the study focused on the target group of people with learning disabilities with the aim of obtaining information about the characteristics of social networks and the availability of social support. It was considered important to obtain the views of participants directly, particularly in view of the growing literature calling for greater involvement in research by people with learning disabilities (Kiernan, 1999). It was also recognised that there can be difficulties in using self report measures with people with learning disabilities (Sigelman, Budd, Winer, Schoenrock & Martin, 1982). The design also allowed for data to be collected from another source. Participants with a learning disability nominated a carer or keyworker who could provide information about their networks and life experiences. For comparison purposes a group of people with a physical disability was also included. A non-experimental cross-sectional within- and between-groups design was therefore employed for this part of the study.

A qualitative methodology was adopted for the second part of the study. The purpose was to establish what the participants with a learning disability thought about their social networks, give them an opportunity to reflect on their responses to the questionnaire measures and obtain their personal perspective on different kinds of relationships. A small group of participants

was therefore seen a second time and interviewed using a semi-structured interview schedule.

2.2 Ethical Approval

Ethical approval for the study was sought from the two Local Research Ethics Committees, which covered the geographical area in which the research was carried out. The procedure was not straightforward. Both committees declined to give approval for the study on first submission but for different reasons, including aspects of research design, question wording of published questionnaires and involvement of GPs. Both committees approved the study when the application was re-submitted (see Appendix 1).

2.3 Participants

For the first part of the study participants were a group of 30 people with learning disabilities, a group of carers or familiar keyworkers who could respond on their behalf and 17 people with physical disabilities. Initial investigation into statistical power and sample size on the basis of published data about the social support measures (Lunsky & Benson, 1997; 1999) suggested a sample size of at least 30. Ideally the sample size would therefore have been larger for the physical disability group but they proved more difficult to recruit than anticipated.

2.3.1 Learning disability group

Participants were recruited into the study on the basis of the following criteria:

- Attendance at a day centre for people with learning disabilities (and therefore not in full-time employment)
- Mild learning disability
- Able to hold a simple conversation
- Age range 18 to 60 years.

The exclusion criteria were:

- Active mental illness or challenging behaviour of such a severity as to preclude participating in a one-to-one interview.

The extent of the learning disability was not directly assessed. The staff at the day centres identified potential participants on the basis of the information they had received from the researcher.

2.3.2 Physical disability group

The following inclusion criteria were used:

- Attendance at a day centre for people with physical disabilities
- Able to hold a simple conversation
- Age range 18 to 60 years
- Moderate to severe physical disability.

The exclusion criteria were as follows:

- Learning disability in addition to the physical disability
- Active mental illness or challenging behaviour of such a severity as to preclude participating in a one-to-one interview.

The criteria for the physical disability group were kept deliberately broad and the nature of the disability left unspecified in order not to restrict numbers of potential participants.

2.3.3 Informant group

Participants with learning disabilities identified someone who cared for them, either in a paid capacity or as a family member, who would be able to provide information on their behalf. The only criteria for inclusion were that the person identified knew the participant well and that the participant was happy that they were approached. Most of the informants were either parents of the participant or residential care staff.

For the second part of the study six of the original group of participants were seen again. The method of theoretical sampling (Pidgeon, 1996) was utilised in order to ensure a rich variety of responses.

The combination of qualitative and quantitative techniques in the same study provided triangulation and complementarity (Hammersley, 1996).

2.4 Recruitment

Day centre managers were approached in the first instance and the outline of the study was explained. If they were prepared for their centre to be included as a source of potential participants, they were given a brief research summary, information sheets (see Appendix 2) and consent forms (see Appendix 3). It was explained that the researcher would not know the names of potential until they had given their consent. The day centres were asked to provide an independent witness to explain the research and countersign the consent form.

Once consent forms had been signed, the names of potential recruits were passed on to the researcher, who then made individual appointments at the person's day centre.

The informant group was recruited once the participant with a learning disability had completed the first interview. The name of a keyworker or carer was obtained from the participant during the interview and contact details were verified with the day centre staff. The first approach was by telephone, followed by sending an information sheet (see Appendix 2).

2.5 Measures

The present study drew upon research conducted in North America by Lunsky and colleagues on the social support and social networks of people with learning disabilities (Lunsky & Benson, 1997; 1999; Lunsky &

Havercamp, 1999) and used some of the same measures. All the measures were chosen either because they had been specifically designed with a learning disability population in mind (and had been used in recently published studies) or, as in the case of the Circles task, they were considered appropriate for people with learning disabilities without significant adaptation. Both self-report and informant measures were used for the learning disability group. The comparison group completed self-report measures only. Table 1 summarises the use of different measures.

Table 1: A summary of measures used.

| Measure | Devised by | Administered to* | Description |
|------------------------------------|----------------------------|-------------------------|---|
| Social Support Self-Report | Lunsky & Benson (1997) | LD, PD | Self-rated measure of social support |
| Circles Task | Antonucci & Akiyama (1987) | LD, PD | Visual representation of network structure |
| Functional Support Interview | Felton & Berry (1992) | LD, PD | Self-rated measure of functional support |
| Life Experiences Checklist | Ager, (1998) | PD, Informant | Checklist measuring life experiences and integration |
| Social Circles Questionnaire | Lunsky & Benson, (1997) | Informant | Informant-rated measure of social support provided to adults with learning disabilities |
| Semi-structured interview schedule | Author | LD Sub-group | Includes questions about responses to the other measures and different kinds of relationships |

* LD: learning disability group; PD: physical disability group

2.5.1 The Social Support Self-Report (SSSR)

The SSSR (see Appendix 4) provides a self-rated measure of social support. It was adapted by Lunsky & Benson (1997) from the Reiss-Peterson Social Support Self-Report for Mentally Retarded Adults (Reiss & Benson, 1985). The original scale covered three sources of support (family, friends and romantic partner); a fourth source (staff) is included in the SSSR. The instrument is in two parts. In the first part respondents are asked questions about family members, friends, boy or girlfriends and staff. The aim of these questions is to provide basic demographic details and information on the composition of the respondent's network.

In the second part of the SSSR the quality of support from each source is evaluated and scored. Items measuring reciprocity of support are also included. An example of an item is "How often do you talk to your friends about your feelings?" A three point Likert-type scale is used for responses with 0 = not at all, 1 = sometimes and 2 = a lot.² The maximum score for each support source is 10 and for the scale as a whole 40, with higher scores indicating greater amounts of social support.

Administration of the entire scale begins with a screening procedure of two items, using the same Likert-type response scale.

² Three colour-coded cards are used with the response choices on them to be placed in front of participant. Response choices can be presented in random order to control for response biases.

Reliability and validity

Lunsky & Benson (1997) used the SSSR to assess the reliability of ratings of social support completed separately by adults with learning disabilities and their care staff. Internal consistency of the SSSR ranged from a Cronbach's alpha of .55 to .85 for the different sources of support and total scores.

Significant correlations were obtained between the two self-report measures used in the study (the SSSR and Harter's (1985) "People in My Life" scale) for total scores and scores for the support sources of family, friends and partners. Lunsky & Benson (1997) concluded that individuals with mild learning disabilities report social support "with some consistency, within a measure, across measures and generally in accordance with staff perceptions" (Lunsky & Benson, 1997, p. 284)

2.5.2 The Circles Task

The Circles Task (see Appendix 5) (Antonucci & Akiyama, 1987) is based on the life course or convoy model of social support (Kahn & Antonucci, 1980). It consists of a social network map and three questions about the people who are close and important to the respondent. The purpose is to provide information on the size and nature of a person's social network. The social network map comprises three large concentric circles on an A4 sheet with "Me" ("you" in the original version) positioned in the centre of the innermost circle. The accompanying questions encourage the person to consider in turn the people who would fit in the circles. The first question, for example, asks

about the people who are so close that “it is hard to imagine life without them”.

Reliability and validity

Antonucci & Akiyama (1987) used the circles technique in a large study of 718 adults aged 50 and over and reported the procedure capable of generating detailed descriptions of the structural support characteristics of their sample. No details of statistical reliability were provided.

The procedure would appear to have good face validity as a measure of a person's social network and who is important in their life.

2.5.3 The Functional Support Interview (FSI)

The FSI (see Appendix 6) consists of six questions describing things people do for others. The purpose of the FSI is to identify which network members provide which types of support. Respondents are asked to name up to three people for each item and prompted by asking if there is anyone else if they supply fewer than three names. The FSI was developed by Felton & Berry (1992) based on six “social provisions” seen as critical for mental health (Weiss, 1974, cited in Felton & Berry, 1992). The questions ask respondents about whom they can count on for sympathy and understanding (attachment), pleasant companionship (social integration), help with household or personal tasks (reliable alliance), or advice if needed (guidance); if there was someone who recognised their abilities (reassurance of worth); and if there was

someone who relied on them for at least part of their care (opportunity for nurturance).

Reliability and validity

Felton & Berry (1992) used the FSI in their study of groups as network members. Their study included 82 users of a geriatric clinic. No information was reported on the psychometric properties of the FSI.

2.5.4 The Social Circles Questionnaire (SCQ)

The SCQ (see Appendix 7) is a 64-item scale for informants to rate the social support of adults with a learning disability. Fifty-six items measure positive social support and eight items measure the stress or strain associated with interpersonal relationships (Lunsky & Haverkamp, 1999). The questionnaire was designed to be comprehensive yet easy to complete and less time consuming than a detailed interview. It measures frequency of support, network size and composition as well as support quality and degree of reciprocity (Lunsky & Benson, 1999). Four support sources are targeted: family, workers (staff), friends and romantic partners. Network size is determined by rating the number of people involved in each of the four support sources. The remaining items address different types of social support, such as problem solving support, instrumental support and nurturance. Examples of positive support items include “friend(s) show day-to-day concern” and “family helps with practical issues”. An example of an item measuring negative social support or social strain is “person is upset/frustrated after visits”. Responses are rated on a Likert-type scale

ranging from 0 = “never” to 4 = “very often” with an additional “don’t know” category. The maximum score for each support source is 56 and for the entire scale 224, with higher scores indicating greater amounts of social support. Social strain is computed separately, with a maximum score of 32.

Reliability and validity

The reliability and validity of the SCQ have been addressed by the authors of the scale (Lunsky & Benson, 1997, 1999; Lunsky & Haverkamp, 1999). In their 1997 study, Lunsky and Benson used the SCQ alongside two other previously published staff measures (the Meins’ Interview for Social Support in Mentally Retarded Adults (Meins, 1993) and the Illinois-Chicago Informant Rating Scale for Social Support (Reiss & Benson, 1985)) and two self-report measures (the Social Support Self-Report (Lunsky & Benson, 1997) and the modified “People in my Life” scale (Harter, 1985)). The SCQ was considered to be a valid measure of social support. The internal consistency was found to be excellent (Cronbach’s Alpha ranging from .87 to .95 according to support source). Consistency across instruments was found to be good for total scores with significant correlations, $p < .005$, reported for the three staff measures. On the whole self-ratings agreed with staff-ratings, especially for ratings of family and partner support.

Lunsky & Benson (1999) have also addressed inter-rater and test-retest reliability. Agreement between raters was found to be only moderate. The Pearson product moment correlations were lower for the support sources “workers”, “romantic partners” and “friends” (ranging from .41 to .48) than for

“family” (.71). The second raters were not necessarily from the same setting or background and the lower inter-correlations might have reflected varied interpretations of the different raters (Lunsky & Benson, 1999). Test-retest reliability was found to be high, with correlations ranging from .83 to .93 for the different support sources and the total scores.

2.5.5 The Life Experiences Checklist (LEC)

The LEC (see Appendix 8) was developed by Ager (1998) as a means of gauging the extent to which an individual enjoys experiences common to many other members of the population. The LEC is a 50-item checklist of statements divided into five subsections: home, leisure, relationships, freedom and opportunities. Examples of the statements are “My home is well decorated” and “I choose my own clothes”. The checklist is designed to be completed either by the respondent or by someone on their behalf. The LEC is described as a measure of “quality of life”, although Ager (1998) advises using the term sparingly and acknowledges that the LEC “concerns itself centrally with the activities and experiences of a client, and only tangentially with their subjective well-being” (Ager, 1998, p.9). It was considered to be an appropriate measure of integration for the purposes of the present study. Norms are available for a general population sample (N=410).

Reliability and validity

Ager (1998) reported test-retest reliability of .93 for the LEC overall, between .91 and .96 for the different domains for undergraduates completing the

checklist a second time after a week's interval; and inter-rater reliability of between .93 and .97.

As well as noting the high degree of face validity of the LEC as a measure of life experience, Ager(1998) provided evidence for construct and predictive validity. A study by Look (1987, cited in Ager, 1998) quoted a correlation of .80 between scores gained by informant interview and self-rating, and good internal consistency. Correlations of between .72 and .78 were reported by Ager (1998) between the LEC and the Index of Community Involvement (a measure of social contact and community integration).

2.5.6 Semi-structured interview schedule

The interview schedule (see Appendix 9) was devised by the author with several purposes in mind. Firstly, it was intended that participants should have the opportunity to voice their opinions about the earlier part of the study and thereby play a more active role in the research process. Secondly, qualitative data would complement the data from the questionnaire measures. Thirdly, the interview aimed to explore the understanding of different relationships, an area not included in the questionnaires.

The format of open-ended questions allowed respondents to say what they thought with greater richness and spontaneity (Oppenheim, 1992). Questions were generated around the themes of friendship and understanding of

different kinds of relationship, including friends, romantic partner and care staff.

The interview schedule was designed to provide a framework which could be adapted as appropriate, for example, by adding additional prompts or altering the order of the questions, thereby allowing the respondent to play a role in determining how it proceeded (Smith, 1995).

2.6 Qualitative methodology

The methodology of choice for this part of the research was content analysis, defined by Krippendorff (1980) as “a research technique for making replicable and valid inferences from data to their context”. Such an approach would reveal the ideas of each of the six participants and be used to compare the interviews. Content analysis has a long history and has been widely used in mass media communication research using material such as newspapers or broadcasts (Krippendorff, 1980). It allows for quantitative measures, such as frequency counts of particular kinds of words or phrases, to be applied to qualitative data. Content analysis differs from some other qualitative methods in not being concerned with theory generation and in emphasising reliability and validity (Pidgeon, 1996). Although pre-designed coding schemes are often utilised in content analysis, none was identified in the literature as appropriate for this population and area of interest. A coding scheme was developed through familiarity with the data along the lines suggested by

Boyatzis (1998). Text units were defined by meaning and a theme analysis conducted on the data (Boyatzis, 1998).

Reliability and validity

The issues of reliability and validity in qualitative research have been the subjects of some debate (Henwood & Pidgeon, 1992). Reliability in thematic content analysis is concerned with consistency of observation, labelling and interpretation rather than verification which, it could be argued, is a positivist notion (Boyatzis, 1998). In the present study reliability was assessed by giving a sample of the transcribed text (approximately 10 percent of the total) to an independent rater and asking them to code chunks of text according to given codes. Inter-rater reliability was then calculated using Cohen's kappa.

According to Tindall (1994) validity in qualitative research has to do with the adequacy of the researcher to understand and represent people's meanings. In some ways therefore it becomes a personal process. In the present study the following issues relevant to validity and evaluation of qualitative research were taken into account:

- Triangulation (Redfern & Norman, 1994) is the use of several methods or vantage points to measure a single construct for completeness or confirmation. The present study was designed to employ different data sources (for example, participant and informant) and methods (self-report questionnaire and semi-structured interview).
- Grounding in examples (Elliott, Fischer & Rennie, 1999). Authors are advised to provide sufficient examples of the data to illustrate both

procedure and categories or themes to enable the reader to evaluate their findings. In the present study examples of each theme were given in the form of verbatim quotes and a selection of transcript made available (see Appendix 10).

- **Auditability.** There needs to be a chain of evidence from extracted themes and interpretations back to the original transcript which is open to external audit (Turpin, Barley, Beail, Scaife, Slade, Smith & Walsh, 1997). As for grounding, examples and explanations were given to aid the process of auditability.

2.7 Procedure

2.7.1 Piloting

The questionnaire measures and semi-structured interview were piloted on a woman with a learning disability living with her family. The informant measures were piloted on a colleague who worked in residential care with people with learning disabilities. Minor changes to the wording of some items on the questionnaires were made as a result; these were mainly to Anglicise words and phrases.

The item on the SSSR “Do you have any staff?” had been altered to “Is anyone employed to care for you?” as a result of comments from one of the two Ethical Committees. However in the pilot the respondent was unclear about the revised item and it was decided to give the item in the revised format initially and then if necessary give the item in the original wording as

well. An additional item was added to the SSSR screen as in the pilot the respondent never went to the cinema and therefore gave the same answer (“not at all”) to both items. It was considered that this could be a frequent response pattern amongst both the learning disability and physical disability groups and would not discriminate between those respondents who genuinely understood the questions and those who might be repeating the last response option.³ The item “How often do you have a cup of tea or coffee?” was therefore added in the expectation of obtaining a variety of responses.

The piloting procedure was particularly useful in identifying an issue of administration and scoring of the SSSR. The woman who completed the pilot lived with her mother and sister. Her relationship with her sister was very supportive but she had a strained relationship with her mother. She felt she got on better with her father than her mother but because there had been a difficult separation between the parents, she had only minimal contact with him. Completing the second part of the SSSR for any one of these key family members would not have presented an accurate view of the situation. For example had she completed it with her sister in mind, the score for the support source Family would have been high, but if she had completed it with her mother in mind the score would have been very low. Completing it for each in turn would have meant altering the scoring procedure. The advice of one of the authors was sought (Lunsky, personal communication) and the

³ The questions were phrased as follows: “How often do you go to the pictures – a lot, sometimes or not at all?”

procedure amended accordingly. The second part of the questionnaire was introduced with the words “Now thinking about your family....” In this way the decision about how to perceive the family or who is most important within the family was left to the respondent.

2.7.2 Procedure for first Interview

Day centre managers and their staff identified who might be suitable for the study. Participants were contacted once the study had been explained to them by staff and they had signed the consent form (see Appendix 3) in the presence of an independent witness. Staff used the information sheet (see Appendix 2), which was written in simple and straightforward language, to explain the research and what participation entailed. Potential participants were encouraged to take the information sheet home with them and discuss it further with a carer or relative who was not involved with the study. It was suggested to the day centre managers that the independent witness could be from a separate organisation such as the local citizen advocacy project.

2.7.3 Informed Consent

Recent research has highlighted some of the difficulties inherent in obtaining fully informed consent from people with learning disabilities (McCarthy, 1998; Arscott, Dagnan & Stenfert Kroese, 1998). Ethical committees rightly demand written evidence of consent but the extent to which it is meaningful for someone who is unable to read the consent form or understand what it means to do research in terms of data analysis, dissemination of results and

publication is debatable. The capacity to give consent may be affected by the tendency to acquiesce and desire to please as well as specific cognitive difficulties (Clare & Gudjonsson, 1995).

All participants in the present study received information sheets that included details of consent issues and options for withdrawal (see Appendix 2). The participants with a learning disability were also asked a series of questions at the start of the first interview to assess their understanding of the nature of the research and consent issues. The questions relating to consent were identical to those used by Arscott et al (1998) in their study, which investigated the ability of people with a learning disability to consent to psychological research. The questions covered what the researcher would be talking to the participant about, how many times they would be seen, good and bad things about talking to the researcher and what the participant could do if they wished to withdraw. A further set of questions was asked to assess "yea-saying" and acquiescence. These were derived from those used by Gratton (1999).

The information sheet was read to the participant again, this time by the researcher. The consent and acquiescence questions were then given. The questions were scored 0 for an irrelevant or incorrect answer, 1 for a partially correct answer or answer with some face validity and 2 for a wholly correct answer.

The interview proceeded if at least half of the questions were answered appropriately. In cases where an uncertain or incomplete response was given the correct information was provided.

2.7.4 Completion of measures.

The order of administration of the measures was firstly the Circles Task, then the SSSR, followed by the FSI. The physical disability group followed these by the LEC. The informant group completed the SCQ followed by the LEC. In all cases the interviews lasted between 20 and 45 minutes. At the end of the interviews participants were debriefed by being thanked for taking part and asked if they had any questions. Participants with a learning disability were reminded that some of them might be contacted again to complete a follow-up interview.

2.7.5 Procedure for second interview

Six of the participants were selected for a second interview. Their consent was sought verbally and they were reminded that they could withdraw at any time. Permission to tape-record the interviews was confirmed (it had been explained in the information sheet that if they were seen again they would be asked if the interview could be taped). Confidentiality was explained in simple terms. The interviews lasted between 20 and 45 minutes. At the end of the interview the participant was reminded about confidentiality, thanked for taking part and asked if they had any comments or further questions.

All six of the participants gave consent for the interviews to be audiotaped. The interviews were transcribed verbatim and analysed for themes using a thematic content analysis (Boyatzis, 1998). Each transcript was read and re-read to ensure familiarity with the data. The stages and steps followed were those recommended by Boyatzis (1998) for a data-driven, inductive approach to thematic analysis. The analysis involved reducing the raw information by creating outlines for each transcript (see Appendix 11), identifying themes from the outlines, comparing the themes across the sample, creating a code and determining reliability.

A theme is defined by Boyatzis (1998) as “a pattern found in the information that at the minimum describes and organises the possible observations or at the maximum interprets the aspects of the phenomenon.” (p.161). Themes may be identified at either the manifest or latent level according to whether they are directly observable from the data or underlying phenomenon. At its simplest a code is a list of themes, at a more complex level a code may involve themes, indicators and qualifications that are causally related. In the present study, once preliminary themes had been identified from the first two transcripts a simple code was developed. The code was applied by the author and an independent rater to the same selection of material to assess reliability, which was computed using the Kappa statistic. Once reliability had been determined the code could be validated through application to the remaining raw information.

3 RESULTS

Demographic data will be presented first followed by the results of the analysis of the quantitative data. The first two research questions and the hypothesis will be addressed in turn. The characteristics of social networks and social support available to the group with learning disabilities will be described and comparisons drawn with previous research and with the group of people with physical disabilities. The qualitative analysis of the semi-structured interviews will then be presented and the second and third research questions will be considered.

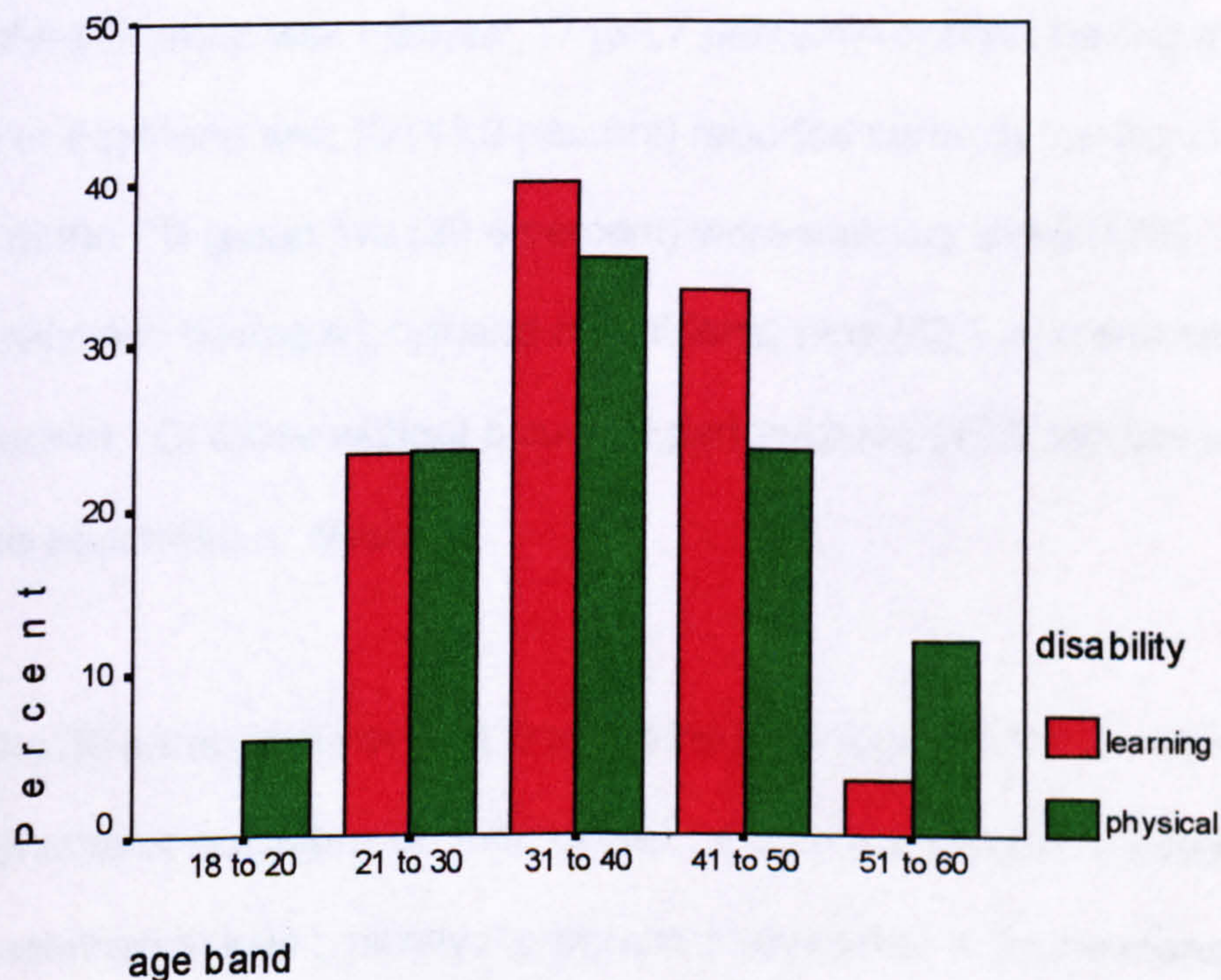
3.1 Demographics

The learning disability (LD) group consisted of 30 people drawn from four day centres for people with learning disabilities. Two people had been excluded at an early stage of the interview, one because he was over 60 and therefore did not meet the age criterion, the other for getting all but one of the consent and acquiescence questions incorrect and failing the screening questions. All 30 participants completed the first part of the study; six were seen for a follow-up interview.

There were 15 men and 15 women in the group. Their ages ranged from 22 to 59 years, with a mean age of 36.37 (SD 8.97). The men ranged in age from 22 to 48 years, with a mean age of 34.67 (SD 8.58) while the women ranged in age from 23 to 59 years, with a mean age of 38.07 (SD 9.32).

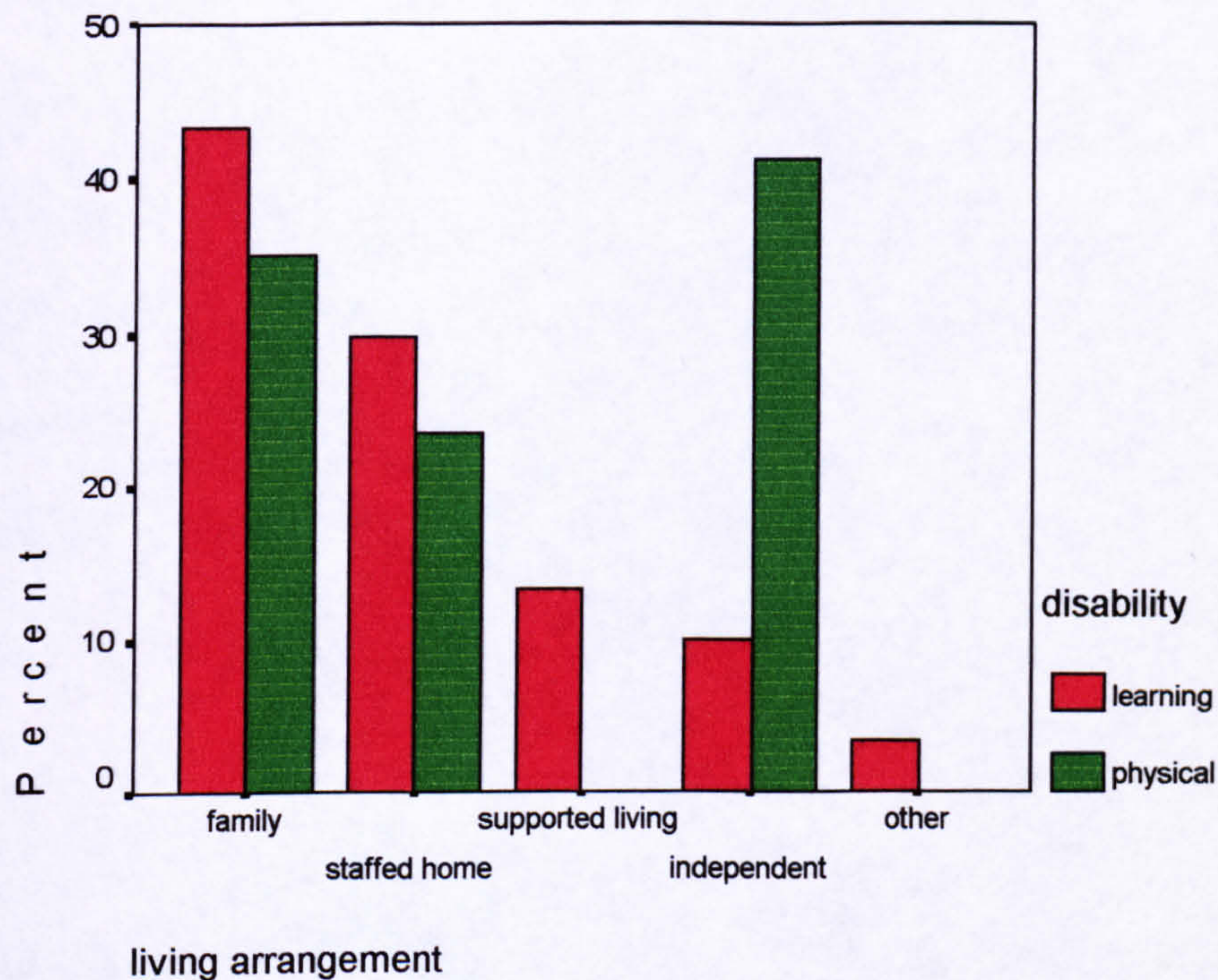
The physical disability (PD) group consisted of 18 people drawn from a social services day centre for people with physical disabilities, two independent day centres, which also provided services for people with disabilities, and two residential homes for the disabled. The data from one person were excluded because they were over 60 and therefore did not meet the age criterion. The remaining 17 in the PD group consisted of 11 women and six men. Their ages ranged from 19 to 58 years, with a mean age of 36.94 (SD 11.66). The men ranged in age from 27 to 58 years, with a mean age of 42.17 (SD 11.96) while the women ranged in age from 19 to 48 years, with a mean age of 34.09 (SD 11). Figure 1 shows the distribution of ages of participants across five age bands.

Figure 1. Age distribution of participants.



Participants lived in a variety of settings. Figure 2 shows the different living arrangements for each group.

Figure 2. Living arrangement of participants.



None of the LD group was married, 17 (56.7 percent) reported having a girlfriend or boyfriend and 13 (43.3 percent) reported currently having no partner. In the PD group five (29.4 percent) were married, three (17.6 percent) reported having a boyfriend or girlfriend, nine (52.9 percent) currently had no partner. Of those without a current partner three (17.6 percent of the total) were separated or divorced.

Each of the 30 participants in the LD group had nominated a family member or carer to answer questions on their behalf. For those living in residential care the nomination was typically the person's keyworker or home manager.

For those living with their family, parents were invariably nominated and interviews conducted with the participant's mother (although in several cases fathers were also present and contributed to the discussion). In one case where parents had been nominated and had initially agreed to be interviewed, they were unable to take part because of family illness and a keyworker at the day centre took on the role of informant. For those participants who were living independently or in supported living most of the informants were day centre staff. In one case the informant was a member of staff from the residential setting where the person used to live before moving into her own flat.

Informants were asked to complete some additional details about the person concerned including how long they had known them, whether they had a psychiatric diagnosis and their level of learning disability. Because of the obvious differences in length of time a parent or a member of staff would have known the person with a learning disability, the length of time known is given separately for three groups. Thus for staff the mean length of time known was 4.24 years (SD 3.27), for parents it was 31.17 years (SD 6.77) and for others 5.5 years (SD 0.71).

Only one person was rated by the informant as having a psychiatric diagnosis and was described as being "paranoid".

The informants classified 19 of the 30 participants as having a mild learning disability and 11 as having a moderate learning disability.

The PD group had a range of disabilities, including spina bifida, cerebral palsy and multiple sclerosis. Although they were not asked directly about their disability and information on diagnosis was not requested, some participants volunteered this information. It was not known whether the group included people with an acquired disability, for example as a result of a road traffic accident. However centre managers were asked not to propose people who were known to have impaired cognitive functioning as a consequence of head injury.

3.2 Consent

The number and percentage of correct and partially correct responses to the consent questions are given in Table 2, together with the comparable percentages obtained by Arscott et al (1998). Correct or partially correct answers were given by at least 70 percent of the sample on four out of the five questions, which suggests that it is possible to obtain meaningful consent from people with learning disabilities.

Table 2. Questions asked to determine ability to consent.

| Question number | Question | Number and percentage responding correctly or partially correctly (score of 1 or 2) | Results from Arscott et al (1998) |
|-----------------|--|---|-----------------------------------|
| 1 | What will I be talking to you about? | 24 (80%) | 92.5% |
| 2 | How many times will I want to talk to you? | 25 (83.3%) | 75% |
| 3 | Are there any good things about talking to me? | 11 (36.6%) | 27.5% |
| 4 | Are there any bad things about talking to me? | 21 (70%) | 2.5% |
| 5 | What can you do if you decide that you don't want to talk to me anymore? | 24 (80%) | 42.5% |

The most discrepant response was found for question 4 (“Are there any bad things about talking to me?”) which was answered correctly or partially correctly by 70 percent in the present study but only 2.5% in the study by Arscott et al (1998).

3.3 Acquiescence

Four additional questions derived from Gratton (1999) were used to assess “yea-saying” and basic understanding (Table 3).

Table 3. Questions asked to assess acquiescence.

| Question number | Question | Number and percentage responding correctly |
|-----------------|--|--|
| 6 | Can I ask how old you are? How old are you? | 26 (86.7%) |
| 7 | Are you over 60? | 26 (86.7%) |
| 8 | Do you come here at weekends? ^a | 29 (96.7%) |
| 9 | Are you married? ^b | 30 (100%) |

^a All participants were interviewed at a day centre, which was closed at weekends.

^b This question appeared in the first part of the Social Support Self Report. The correct response was “no” as none of the Learning Disability group was married.

3.4 Statistical Analysis

Statistical analysis was completed using SPSS for Windows, version 9.

Non-parametric tests were used to compare the target and comparison groups. There were two reasons for choosing non-parametric methods over the more statistically powerful parametric tests: firstly, the two groups were of unequal size and secondly, exploratory data analysis revealed outliers and skewness in some of the data.

However a parametric test was chosen to compare mean scores of the sample with specified population means, on the basis that the larger population met the distribution assumptions necessary for parametric statistics.

Significance levels were set at $p < .05$.

3.5 Research Question 1

What are the characteristics of social integration (as measured by the Life Experiences Checklist), social networks (as measured by the Circles technique), and social support (as measured by the Social Support Self Report, the Functional Support Interview and the Social Circles Questionnaire) among people with learning disabilities?

3.5.1 Social integration

Social integration was measured by the LEC (Ager, 1998). Table 4 shows the median scores obtained by the LD group for the LEC and for each of its five

subsections. Higher scores denote a better quality of life as defined by the LEC.

Table 4. Scores obtained on the Life Experiences Checklist (n=30)

| | Home | Leisure | Relationships | Freedom | Opportunities | Total |
|-----------------|-------------|-------------|---------------|-------------|---------------|--------------|
| Mean (SD) | 8.73 (1.47) | 6.33 (1.71) | 5.27 (1.51) | 7.73 (1.46) | 8.47 (1.07) | 36.53 (3.94) |
| Median | 9 | 6 | 5 | 8 | 9 | 36.5 |
| Minimum | 3 | 3 | 2 | 4 | 6 | 27 |
| Maximum | 10 | 9 | 9 | 10 | 10 | 45 |
| Range for scale | 0 – 10 | 0 - 10 | 0 – 10 | 0 – 10 | 0 – 10 | 0 – 50 |

The data were compared with a general population sample obtained from self-rated LECs completed by 410 householders across urban, suburban and rural communities in the Leicester area (Ager, Annetts, Barlow, Copeland, Kemp, Sacco & Richardson, 1988). One-sample t-tests were used to compare means (Table 5).

Table 5. LEC: comparison with general population.

| | Ager et al (N=410) Mean | Present study (n=30) Mean | T | d.f. | Sig. (2-tailed) |
|---------------|-------------------------|---------------------------|-------|------|-----------------|
| LEC total | 34.8 | 36.53 | 2.41 | 29 | .022* |
| Home | 8.0 | 8.73 | 2.80 | 29 | .009** |
| Leisure | 4.6 | 6.33 | 5.56 | 29 | .000*** |
| Relationships | 6.6 | 5.27 | -4.85 | 29 | .000*** |
| Freedom | 8.0 | 7.73 | -1.00 | 29 | .326 |
| Opportunities | 7.5 | 8.47 | 4.93 | 29 | .000*** |

* $p < .05$; ** $p < .01$; *** $p < .001$

The results obtained suggest that social integration was significantly better than in Ager et al's (1988) study in all areas apart from Freedom, where no significant difference was obtained, and Relationships, where the quality of

life was significantly lower. These results contradict those expected in all areas apart from Relationships.

Comparison was also made with a more recent study of 85 clients with learning disabilities living in ordinary housing (Hughes, McAuslane & Schur, 1996) (Table 6).

Table 6. LEC: comparison with learning disability sample.

| | Hughes et al (N= 85) Mean | Present study (n=30) Mean | t | d.f. | Sig. (2-tailed) |
|---------------|---------------------------------|------------------------------|-------|------|--------------------|
| LEC total | 37.0 | 36.53 | -.65 | 29 | .521 |
| Home | 8.9 | 8.73 | -.63 | 29 | .530 |
| Leisure | 5.9 | 6.33 | 1.39 | 29 | .175 |
| Relationships | 5.7 | 5.27 | -1.57 | 29 | .126 |
| Freedom | 8.5 | 7.73 | -2.87 | 29 | .007** |
| Opportunities | 8.0 | 8.47 | 2.38 | 29 | .024* |

* $p < .05$; ** $p < .01$

No significant difference was found in terms of overall life experiences between the present study and Hughes et al (1996). There were no significant differences in the domains of Home, Leisure and Relationships, although significant differences were found in the remaining two domains. Freedom was significantly lower for the present study and Opportunities significantly higher.

3.5.2 Social networks

The size and nature of the social networks of the participants were assessed using the Circles technique derived from the convoy model of social support

(Kahn & Antonucci, 1980). The 30 respondents nominated a total of 350 network members, resulting in a mean network size of 11.67 members (*SD* 8.5). Differences in circle placement and relationship between the respondent and the network member were examined. The mean number of network members in the innermost circle was found to be 4.87 (*SD* 3.77), for the middle circle the mean was 3.47 (*SD* 2.57) and for the outer circle 3.33 (*SD* 4.22). Previous studies using the circles technique with older adults reported mean network sizes of 8.9 (*SD* not reported) (Antonucci & Akiyama, 1987) and 5.3 (*SD* 3.4) (Felton & Berry, 1992), suggesting that the LD group reported larger networks than groups of older adults. A mean network size of 7.1 was reported by Krauss et al (1992) in a large study of adults with learning disabilities living with their families.

Network members were categorised according to whether they were immediate family (i.e. parent or sibling), extended family, boyfriend or girlfriend, friend with a learning disability, other friend, residential or day staff or other. Table 7 presents the relationship of network members to respondents. Family members made up the majority of the support network (40.28%) followed by friends (28%) (who were mostly friends with a learning disability) and members of staff (21.14%).

Table 7. Composition of support network.

| | Imm family | Extend family | Boy/girlfriend | LD Friends | Other friends | Day Staff | Resid Staff | Other | No. |
|---------------|--------------|---------------|----------------|--------------|---------------|--------------|-------------|------------|-----|
| Inner circle | 49 33.56% | 30 20.54% | 6 4.11% | 20 13.7% | 6 4.11% | 23 15.75% | 4 2.74% | 8 5.48% | 146 |
| Middle circle | 7 6.73% | 31 29.8% | 1 0.96% | 31 29.81% | 4 3.85% | 14 13.46% | 7 6.73% | 6 5.77% | 104 |
| Outer circle | 8 8% | 16 16% | 2 2% | 27 27% | 10 10% | 20 20% | 6 6% | 14 14% | 100 |
| Total network | 64 18.28% | 77 22% | 9 2.57% | 78 22.28% | 20 5.71% | 57 16.28% | 17 4.86% | 28 8% | 350 |
| | 40.28% | | | 28% | | 21.14% | | | |

3.5.3 Social support

The nature and extent of social support available to participants were assessed using the Functional Support Interview (Felton & Berry, 1992), the Social Support Self Report (Lunsky & Benson, 1997) and the Social Circles Questionnaire (Lunsky & Benson, 1997). The first two of these were administered directly to the participant and the third was administered to an informant responding on their behalf.

Respondents cited members of staff as providers of functional support most frequently. As many as 53.1percent of the 322 nominations were either day centre or residential staff. The next most frequently nominated group were friends (18 percent) of whom the great majority were friends with a learning disability. Family members comprised 14.6 percent of nominations and boy or girlfriends 2.8 percent. The remaining 11.5 percent were categorised as “other” and included neighbours, college tutors, GPs and helpers at social clubs for people with learning disabilities.

Participants with learning disabilities and their carers reported that support was received from family, staff, friends and partners with some differences in level of support between sources (see Table 8 and Table 10). The support source Partner received the lowest ratings from both participants and informants.

Reciprocity items are included in each of the scales Family, Staff, Friends and Partner. The score for Reciprocity is calculated across the other four scales and is therefore not included in the total score.

Table 8. Means and SDs for ratings by support source (self-rated).

| | Family Mean (SD) | Staff Mean (SD) | Friends Mean (SD) | Partner Mean (SD) | Reciprocity Mean (SD) | Total Mean (SD) |
|---------------------------------------|---------------------|--------------------|----------------------|----------------------|--------------------------|--------------------|
| SSSR (self rated) n=30 | 6.37 (1.97) | 6.7 (1.78) | 6.13 (2.54) | 3.83 (3.57) | 3.17 (2.1) | 23.03 (5.66) |
| Range for scale | 0 - 10 | 0 - 10 | 0 - 10 | 0 - 10 | 0 - 8 | 0 - 40 |

The data for self-rated social support were compared with North American data obtained from one of the authors of the SSSR (Lunsky, 1997) using one-sample t-tests. The results of the comparison are shown in Table 9.

Table 9. SSSR one-sample t-tests.

| Support source | Lunsky N=84 Mean (SD) | Present study Mean (SD) | <i>t</i> | d.f. | Sig. (2-tailed) |
|----------------|--------------------------|----------------------------|--------------|-----------|--------------------|
| Family | 5.49 (2.80) | 6.37 (1.97) | 2.43 | 29 | .021* |
| Staff | 6.51 (2.51) | 6.7 (1.78) | .583 | 29 | .564 |
| Friends | 6.45 (2.34) | 6.13 (2.54) | -.682 | 29 | .501 |
| Partner | 3.08 (4.06) | 3.83 (3.57) | 1.155 | 29 | .258 |
| Reciprocity | 3.30 (2.18) | 3.17 (2.1) | -.347 | 29 | .731 |
| Total | 21.53 (7.10) | 23.03 (5.67) | 1.453 | 29 | .157 |

* $p < .05$

A significant difference was found between the present study and the North American study for the support source Family, otherwise there were no significant differences for the separate sources of support or for total support. These results suggest the two groups' ratings were largely similar.

The SCQ includes a "don't know" option for each item. The mean number of "don't knows" for each subsection were .87 for family, 1.53 for staff, 1.57 for friends, .77 for partner and 4.73 for the entire scale. "Don't knows" were treated as missing values initially. However because the presence of a single "don't know" on a subsection caused the entire subsection and overall SCQ score to be excluded from further data analysis, it was decided to include cases where at least 80 percent of the responses were other than "don't know". The missing values were re-calculated as the mean of the remaining subsection or total scores. There were then up to five missing cases on the different subsections of the SCQ and two missing cases for the overall SCQ.

Table 10. Means and SDs for ratings by support source (informant rated).

| | Family Mean (SD) | Staff Mean (SD) | Friends Mean (SD) | Partner Mean (SD) | Reciprocity ^a Mean (SD) | Total Mean (SD) |
|--|----------------------------|---------------------------|-------------------------|---------------------------|---------------------------------------|----------------------------|
| SCQ (inform- ant rated) | 27.16 (12.93) [n=26] | 30.74 (8.13) [n=26] | 21.95 (15) [n=25] | 8.62 (13.69) [n=27] | 15.26 (10.18) [n=27] | 87.88 (28.21) [n=28] |
| Range for scale | 0 - 56 | 0 - 56 | 0 - 56 | 0 - 56 | 0 - 64 | 0 – 224 |

^a Reciprocity scale consists of items from each of the other subscales.

The data were compared with published data (Lunsky & Benson, 1997) using one-sample t-tests. The comparisons are given in Table 11.

Table 11. SCQ one-sample t-tests.

| Support source | Lunsky & Benson Mean (SD) | Present study Mean (SD) | t | d.f. | Sig. (2-tailed) |
|-------------------|---------------------------------|----------------------------|-------|------|--------------------|
| Family | 27.1 (17.3) | 27.16 (12.93) | .024 | 25 | .981 |
| Staff | 42.1 (9.2) | 30.74 (8.13) | -7.12 | 25 | .000*** |
| Friends | 40.6 (11.6) | 21.95 (14.99) | -6.22 | 24 | .000*** |
| Partner | 19.8 (19.1) | 8.62 (13.69) | -4.24 | 26 | .000*** |
| Total | 134 (36.5) | 87.88 (28.21) | -8.65 | 27 | .000*** |

*** $p < .001$

In the present study ratings were significantly lower for the support sources of Staff, Friends and Partner and for social support overall in comparison to

ratings obtained by Lunsky & Benson (1997). No significant difference was found between the means for the support source Family.

Contrary to expectations no significant correlation was found between overall self-rated and informant-rated social support (Spearman's $\rho = .152$, $p = .439$, n.s.). Similarly no significant correlations were found between self-rated and informant-rated support from family (Spearman's $\rho = .302$, $p = .133$, n.s.), staff (Spearman's $\rho = .184$, $p = .368$, n.s.), friends (Spearman's $\rho = -.017$, $p = .935$, n.s.), or partner (Spearman's $\rho = .259$, $p = .097$, n.s.). However a significant correlation was found for reciprocity of support (Spearman's $\rho = .506$, $p = .007$, significant at the .01 level, (2-tailed)).

3.6 Hypothesis

People with learning disabilities will be less socially integrated, have more restricted social networks and fewer sources of social support than a comparison group of people with physical disabilities.

3.6.1 Social integration

Table 12 gives the results of the LEC for the PD group.

Table 12. Scores obtained on the LEC, physical disability group, n=17

| | Home | Leisure | Relation- ships | Freedom | Opportunit ies | Total |
|--------------------|-------------|----------------|--------------------|----------------|-------------------|------------------|
| Mean (SD) | 9 (1.12) | 4.47 (1.84) | 6.76 (2.11) | 8.12 (1.17) | 6.76 (1.92) | 35.06 (21.81) |
| Median | 9 | 4 | 7 | 8 | 7 | 35 |
| Minimum | 7 | 1 | 2 | 5 | 3 | 28 |
| Maximum | 10 | 8 | 10 | 9 | 10 | 42 |
| Range for scale | 0 - 10 | 0 - 10 | 0 - 10 | 0 - 10 | 0 - 10 | 0 - 50 |

Comparisons were made between these results and those obtained by the LD group using the Mann-Whitney test (Table 13).

Table 13. LEC: comparison between LD group (n=30) and PD group (n=17)

| | Home | Leisure | Relationshi ps | Freedom | Opportuniti es | Total |
|---------------------------|------|---------|-------------------|---------|-------------------|-------|
| Z | .754 | -3.148 | -2.846 | -1.079 | -3.217 | -.910 |
| Exact. Sig. (1-tailed) | .217 | .001** | .002** | .144 | .001** | .185 |

**** $p < .01$**

No significant difference was found between the median overall measure of social integration for the two groups. Significant differences were found for the domains Leisure, Relationships and Opportunities. The PD group scored lower for Leisure and Opportunities than did the LD group but scored higher for Relationships.

3.6.2 Social networks

The 17 people in the PD group nominated a total of 521 network members, giving a mean network size of 30.65 (SD 15.69). The mean number of

network members in the inner circle was found to be 8.41 (*SD* 5.57), for the middle circle the mean was 12.41 (*SD* 9.19) and for the outer circle 9.82 (*SD* 10.17). Significant differences were found between the median values for the LD and PD groups using the Mann-Whitney test (Table 14).

Table 14. Comparison of network size, LD and PD groups.

| | Inner circle | Middle circle | Outer circle | Entire network |
|-----------------------|--------------|---------------|--------------|----------------|
| Z | -2.814 | -3.643 | -2.587 | -4.356 |
| Exact sig. (1-tailed) | .002** | .000*** | .004** | .000*** |

***p* = < .01, *** *p* = < .001

The size of the overall network was significantly greater for the PD group. In addition, there were significant differences in the sizes of the inner, middle and outer circles; in all cases the number of network members cited was greater for the PD group. These findings support the hypothesis that people with learning disabilities would have more restricted social networks than would people with physical disabilities.

Looking at the characteristics of the social networks in more detail, significant differences between the two groups were found for numbers of family members and friends, but not for members of day staff (Table 15).

Table 15. Comparison of network members, LD and PD groups (Mann-Whitney).

| | Immed. Family | Extend family | All family | Resid. Staff | Day staff | All staff | Dis. friends | Other friends | All friends |
|---------------------------------|------------------|------------------|---------------|-----------------|--------------|-----------|-----------------|------------------|----------------|
| Z | -2.647 | -2.985 | -3.575 | -1.811 | -1.124 | -.810 | -1.702 | -4.667 | -4.091 |
| Exact Sig. (1- tailed) | .003** | .001** | .000*** | .048* | .133 | .213 | .045* | .000*** | .000*** |

In all cases apart from residential staff the differences were in the direction suggested by the hypothesis, i.e. the network of the LD group was more restricted than that of the PD group.

In contrast to the LD group, friends rather than family members made up the majority of the support network for the PD group. Thus, friends made up 43 percent of the network with almost equal representation of friends with disabilities and friends without disabilities (21.9 percent and 21.1 percent respectively). Family members made up 38 percent of the network and staff 10.6 percent. The remainder of the network consisted of partners (1.3 percent) and others (7.1 percent).

3.6.3 Social support

The PD group made 214 nominations for providers of support on the FSI of whom the majority were family members (29.9 percent). The next most frequently nominated group were members of staff (28.5 percent) followed by friends (20.6 percent). Partners made up 7.5 percent of nominations and the remaining 13.5 percent were categorised as "other".

Comparison between the two groups revealed a few significant differences in terms of median values for the different support sources (Table 16).

Table 16. FSI: comparison between PD and LD groups (Mann-Whitney).

| | Family | Staff | Dis Friends | Other friends | All friends | Partner | Other |
|-----------------------|--------|--------|-------------|---------------|-------------|---------|-------|
| Z | -2.895 | -1.947 | -.805 | -3.456 | -.816 | -1.346 | -.971 |
| Exact sig. (1-tailed) | .002** | .025* | .209 | .001** | .211 | .089 | .169 |

p* < .05, *p* < .01

The PD group cited family and friends without disabilities more often than the LD group. Staff were significantly more likely to be cited more by the LD group than the PD group.

No differences were found between the groups for overall self-rated social support. The PD group reported receiving more social support from their family than did the LD group, otherwise there were no significant differences between the two groups for the subsections of the SSSR (see Table 17).

Table 17. SSSR: comparison between PD and LD groups (Mann-Whitney).

| | Family | Staff | Friends | Partner | Reciprocity | Total |
|-----------------------|--------|-------|---------|---------|-------------|-------|
| Z | -2.284 | -.168 | -.827 | -.105 | -1.122 | -.122 |
| Exact sig. (1-tailed) | .011* | .433 | .208 | .459 | .134 | .454 |

**p* < .05

3.6.4 Impact of living arrangement

Comparison between the LD and PD groups could have been affected by differences found in their living arrangements (see Figure 2). The presence of an association between the qualitative variables disability and living arrangement can be determined by means of the chi-square statistic. The data for living arrangement were collapsed from five categories (family, staffed home, independent, supported living and other) firstly into three categories (family, staffed home and independent or supported living) and then into two categories (family or staffed home and independent or supported living). Examination of the resulting crosstabulations revealed that there were cells with expected counts of less than 5, thereby failing to meet the prescribed minimum requirements for the valid use of the chi-square (Kinnear & Gray, 1999). Grouping the data into two new categories, family and other living arrangement, did meet the requirements for the use of chi-square with the following results: $\chi^2 = .574$, d.f. = 1, n.s. No association was therefore found between disability and living arrangement.

3.7 Research Questions 2 and 3

What do people with learning disabilities think about the social networks and social support available to them?

What is the understanding of people with learning disabilities of different relationships, such as friendship and close personal relationships, and what meaning do they ascribe to their experience of such relationships?

Questions 2 and 3 were addressed using qualitative methodology. Table 18 shows the characteristics of the sub-group selected for the second interview.

Table 18. Characteristics of sub-group.

| Participant number | Sex | Age | Living arrangement | Boyfriend or girlfriend? |
|--------------------|--------|-----|--------------------|--------------------------|
| 1 | Female | 23 | Family | Yes |
| 2 | Female | 31 | Residential | No |
| 3 | Female | 28 | Family | No |
| 4 | Male | 37 | Residential | No |
| 5 | Male | 34 | Residential | No |
| 6 | Male | 31 | Family | Yes |

The first part of the semi-structured interview involved reminding participants of their responses in the earlier interview. Apart from affirmative responses little additional information was forthcoming. Themes identified in the remainder of the interview are presented in the following tables.

Inter-rater reliability was calculated on a sample of 20 text units rated by the author and an independent rater with an agreement of 82.7% (Cohen's Kappa statistic).

Table 19 shows the themes identified from questions about friendship.

Table 19. Themes relating to friendship.

| 1. What does it mean to have a friend? If you had to tell someone else what friendship means what would you say? 2. What's different about best friends? | | | | |
|---|--|---|-------------------------|------------------------------------|
| Label | Definition | Examples from text | Frequency of occurrence | Transcripts in which theme appears |
| 1 Practical support | Someone to go out with, talk to, do things with, provide company | "sit down with them and have a talk with them and have a natter, coffee together" | 18 | 1, 2, 3, 4, 6 |
| 2 Emotional support | Provision of support when upset, understanding, make person feel happy | "they help you when you feel miserable" | 6 | 3, 4, 5, 6 |
| 3 Likeable | Friends are nice people, friends are kind, usually can be trusted | "they're nice people, really kind" "I get on with D really well 'cos she's my best friend" | 7 | 2, 3, 6 |
| 4 Stability | Understanding that friendship can last | "I known her and her mum as well together and um I don't know how long it was but I've known her up to now" | 2 | 1, 6 |

All of the sub-group were able to give definitions of friends or friendship, with the practical aspects of friendship being mentioned most frequently. Most of the participants provided definitions of romantic relationships and understood such relationships as being more than friendship (Table 20).

Table 20. Themes relating to romantic relationship.

| 1. What's different about a friend and a boy/girlfriend? | | | | |
|--|--|--|-------------------------|------------------------------------|
| 2. Is it important to have a boy/girlfriend? | | | | |
| Label | Definition | Examples from text | Frequency of occurrence | Transcripts in which theme appears |
| 1 Practical support | Someone to go out with, talk to, do things with, provide company | "go out with them or go round their house at weekends" | 3 | 1,4, 6 |
| 2 Emotional support | Provision of support when upset, understanding, make person feel happy | "they make you happy" | 2 | 1,4 |
| 3 Intimacy | Understanding of depth of relationship, involvement of closeness or love | "sex, love" "a relationship, it goes more" "the closest one" | 8 | 1, 3, 4, 6 |
| 4 Negative aspects | Expression of negative or ambivalent comments | "Dad says to me not yet, not till I get older" "sometimes they're a pain" | 2 | 2, 5 |

Although few of the group understood the terms “intimacy” or “intimate relationships” without being given a definition, all of them understood the impact of not having close relationships (Table 21). The concept of loneliness was mentioned in only one of the transcripts.

Table 21. Themes relating to intimate relationships.

| 1. What does it mean when people talk about intimacy/intimate relationships? 2. Have you ever had any very close relationships? 3. How do you think people feel when they don't have any close relationships? | | | | |
|--|--|---|--------------------------------|---|
| Label | Definition | Examples from text | Frequency of occurrence | Transcripts in which theme appears |
| 1 Knowledge of meaning of intimacy/intimate relationships | Shows understanding of terms (may be given definition) | "a lot physical, a physical relationship" "you care, again like them trust them" | 4 | 1, 3, 4 |
| 2 Experience of close relationships | Gives examples of close relationships | "I'm like that [gesture] with her, more close" | 8 | 1, 2, 3, 4, 6 |
| 3 Impact of lack of close relationships | Understands impact, expresses feelings of sadness, loneliness etc. | "awful" "angry" "it'd make me feel sad, very sad" | 10 | all |

Some of the group perceived members of staff as fulfilling many of the same functions as a friend, for example as a source of support when upset (Table 22).

Table 22. Themes relating to relationships with staff.

| 1. What about other kinds of friendship? Can you be friends with staff? | | | | |
|--|---|--|--------------------------------|---|
| Label | Definition | Examples from text | Frequency of occurrence | Transcripts in which theme appears |
| 1 Emotional support | Provision of support when upset, understanding, make person feel happy | "staff support us" "if I get really upset sometimes I go to the staff" | 6 | 1, 2, 5 |
| 2 Perception of staff as close friends | Refers to staff in same terms as close friend or family member | "we're more close, very close" | 3 | 1, 6 |
| 3 Negative aspects | Recognition of possible difficulties in making close relationships with staff | "That's hard 'cos you got to be friends, but if, right, they were married, what happens" | 2 | 6 |

Additional themes emerged from the transcripts that were not directly related to a specific question. Participants spoke about the consequences of relationships that had gone badly and the emotional and sexual pressure to which they had been subjected (Table 23).

Table 23. Themes relating to negative impact of relationships.

| Impact of relationships that go wrong | | | | |
|--|--|--|--------------------------------|---|
| Label | Definition | Examples from text | Frequency of occurrence | Transcripts in which theme appears |
| 1 Betrayal of trust | Awareness of being cheated on or betrayed by partner | "I didn't understand why he was lying to me. I didn't understand why" "I won't be able to trust him again" | 19 | 1, 2, 3, 4 |
| 2 Sexual pressure | Describes situations involving sexual pressure (may be implied) | "force you to do things you don't want to do with them" "He knew I couldn't have kids or babies. He didn't like it" "she wants me to make love with her and I said no I don't want to" | 9 | 1, 6 |
| 3 Negative emotional consequences | Describes emotional distress as a result of being let down or break-up of relationship | "I don't want to have a relationship anymore. It really hurts" "I was really crying because that person let me down and it's not nice" | 4 | 1, 3, 4 |
| 4 Lack of privacy | Difficulties associated with privacy and maintaining distance from ex-girl/boyfriend | "if I told them it's going to go round the centre" "I was in the same room [as ex-boyfriend], that makes it difficult" | 4 | 1, 3 |
| 5 Assertiveness | Expresses intent to assert self in face of adversity | "I'll say if it happens again I don't ever want to see you again" | 8 | 1, 4 |

3.8 Key results

Research question 1:

- Overall social integration was found to be significantly greater for the LD group than for the normal population. The LD group scored significantly lower on the domain Relationships.
- A mean network size of 11.67 (*SD* 8.5) was found which was larger than those reported in studies using the same methods with (normal) older adults. The majority of the network consisted of family members, followed by friends with LD and staff.
- Functional social support was provided mainly by staff, then friends with LD, followed by family.
- There was little difference in terms of self-reported social support from staff, family and friends. Ratings were very similar between this study and a North American sample for all sources of support except for family, which was rated higher in the present study.
- There were no correlations between self-rated and informant-rated social support apart from the subscale reciprocity.
- Informant-rated support from the family was similar to a North American sample, otherwise informant ratings were substantially lower.

Hypothesis:

- No overall difference was found between the LD and PD groups for social integration, however the PD group scored significantly lower on Leisure and Opportunities and significantly higher for Relationships.

- The LD group had significantly smaller networks than the PD group whose networks were composed of mostly friends.
- There were no differences between the groups in terms of overall self-rated social support. However the PD group reported significantly more support from family members.

Research questions 2 and 3:

- All of the sub-group gave definitions of friendship, most clearly understood different kinds of relationship.
- Most of the group described negative consequences of relationships.

4 DISCUSSION

The discussion will be presented in three parts: firstly, the methodology will be reviewed, secondly, the results will be discussed and findings related to published research and thirdly, the implications of the research will be discussed in relation to clinical work and future research.

4.1 Review of methodology

4.1.1 Recruitment

The learning disability sample was drawn from day centres and senior staff made the initial selection for possible inclusion in the study. Given the criteria for inclusion, all of the sample were expected to fall into the category of “mild” learning disability (IQ 50 to 70 according to ICD-10), whereas 11 of the 30 were rated by informants as having a “moderate” learning disability and the remaining 19 were rated as “mild”. However, the question about level of functioning clearly caused difficulty for some of the carers. The options presented were “mild learning disability”, “moderate learning disability” or “other”. Both family and other carers admitted to being unsure of the distinction between mild and moderate and some parents were confused by the fact that their son or daughter had attended a school for children with severe learning difficulties. There appeared to be a discrepancy between the understanding of professionals and families, perhaps unsurprisingly given that terminology and classification systems have varied over time and some researchers have used 55 rather than 50 as a cut-off between mild and

moderate disability (Hatton, 1998). Furthermore it could be argued that the use of IQ is in any case a rarefied system: few of the informant group would have had access to IQ levels and even if they had, would not necessarily have understood what they meant. For the present research it was important that those selected were able to give consent, manage in a one-to-one interview and understand the task.

It was intended to recruit the same number of people to the physical disability group as to the learning disability group. However recruitment of the physical disability group proved more difficult than anticipated. Some of the centres that provided services for the physically disabled accepted people who had additional learning disabilities or significant acquired brain damage or catered mainly for an older population. People with physical disabilities may be more difficult to access via day centres because many may choose not to attend and in times of low unemployment more are likely to be in some form of work. Without the constraints of time and geography (the study was limited to the area covered by the ethical committees) it may have been possible to recruit more participants.

4.1.2 Procedure and measures

The procedure presented few difficulties for either the learning disability or physical disability group. The questions asked appeared to be well within the capabilities of the learning disability group. There were no problems with maintaining attention or concentration for the duration of the interview.

The Circles technique was considered to be particularly appropriate for the learning disability group as it involved a visual element. Although most of the participants were unable to read all the names that were put down in the different circles, it was a straightforward procedure to remind them who had been placed where.

For reasons of confidentiality no attempt was made to verify the composition of the network either with the informant or other significant people named by the participant.

More detailed information could have been obtained from the Circles. For example, Antonucci & Akiyama (1987) asked respondents a series of questions concerning both structural and functional characteristics of the first 10 people listed in their network. However as well as adding time to the administration, such questions could have made the procedure too complex for the participants with learning disabilities. Several of the questions used by Antonucci & Akiyama (1987) relied on estimations of frequency or time which are known to be difficult for people with learning disabilities (Finlay & Lyons, 2000).

The measure that presented the most difficulties was the SCQ, which was given to the informant group alone. Difficulties arose when informants felt they had insufficient knowledge of the person with a learning disability in a

different context and therefore answered “don’t know” to a whole section of the questionnaire. This was not necessarily related to the length of time that they had known the person, as it was as likely to occur with parents who felt unable to comment on the level of support their son or daughter received or gave to care staff. One way of minimising the amount of missing information might be to use more than one informant, thereby covering different settings.

Another issue arises from the discrepancies between self- and informant-rated social support. It was not possible to pursue discrepancies with either the informant or the participant because of the need to maintain confidentiality. Possible changes to the design of the study to address this issue include using an informant for the physical disability group as well or using a measure of social support that could be completed by the participants and the informants.

The LEC was used in the present study to provide a measure of social integration. The scale is described by the author, albeit somewhat cautiously, as a measure of quality of life (Ager, 1998). The relatively high scores obtained by the learning disability group in all but one of the domains would suggest they have a high quality of life and are well integrated. However the group obtained comparatively poor scores on the domain Relationships and it could be argued that satisfactory relationships are essential for high quality of life and social integration. Moreover the learning disability group reported more limited social networks in comparison to the physical disability group

suggesting they were less well socially integrated. The LEC may therefore be measuring quantity rather than quality of life experiences.

In the follow-up interviews participants did not, as intended, reflect directly upon their responses to the first part of the study. Reasons for this included firstly, the time lag of several weeks between the first interview when the measures were administered and the second interview. A shorter interval could have ensured that the information from the first interview was easier to recall. Secondly, questions about the participant's own network may have been better placed later on in the interview, once the person was more at ease. Thirdly, a more direct question about what the participant thought about their family and friends and how their situation compared with that of their peers or other people they knew may have yielded more information.

4.2 Discussion of results

4.2.1 Social integration

The extent of social integration of the participants with learning disabilities appeared to be relatively high. The learning disability group scored significantly higher on all the domains of the LEC apart from Freedom, where no difference was found, and Relationships, where they scored significantly lower. With the exception of Relationships, these results go against expectations. However it could be argued that standards of living have generally improved since the 1980's when the standardisation data was collected, which would affect some aspects of quality of life. For example,

since the 1980's use of the telephone has increased, central heating is more common, there is less unemployment and more emphasis on continuing education and skills training. A general population sample questioned in the year 2000 might be expected to score better on the domains affected by these changes. Furthermore the present study was conducted in a largely suburban area characterised by low levels of unemployment and reasonable levels of prosperity.

People with learning disabilities tend to have more leisure time in which to do some of the activities that score on the LEC. The group were found to be more similar to a group of people with learning disabilities studied in the 1990's by Hughes et al (1996), who in turn were found to score significantly higher in the domains of Home, Leisure, Freedom and Opportunities than a group of unemployed and retired people.

No significant difference was found for overall social integration between the learning disability group and the comparison group of people with physical disabilities. The physical disability group had significantly lower scores on two of the domains (Leisure and Opportunities) of the LEC. The severity of the disabilities of the comparison group, most of whom were in wheelchairs, may have contributed to the fact that they scored lower than the target group. The Leisure domain includes items such as participation in sport and going out to the theatre or cinema while Opportunities includes items such as cooking and doing jobs in the home. The majority of the physical disability group, if not in

residential accommodation, were reliant on members of their family (typically parent or spouse) and part-time carers to meet many of their daily care needs.

The results appear to support the view that learning disability services have succeeded in their aims of providing high quality accommodation (in the case of residential provision), a range of opportunities and access to activities in the community and respect for individual freedom, thus achieving social role valorisation (Wolfensberger, 1983). However the picture is different in respect of relationships. The domain Relationships on the LEC was the only one for which the learning disability group scored lower than the normative group. In addition there were significant differences between the learning disability and physical disability groups for Relationships, again with the learning disability group scoring substantially lower.

One reason for these findings could be that it is much harder to help people develop relationships than to provide other aspects of quality of life. Services can be set up in such a way as to ensure people are living in well-decorated homes with their own possessions and that they lead busy lives with plenty of leisure activities. It is less easy to ensure that friendships and relationships are established and maintained. As Firth & Rapley (1990) have argued, often staff confuse provision of leisure and recreational activities with social relationships. There is little evidence that, by themselves, leisure activities are

a good way of extending the social lives of people with learning disabilities (Firth & Rapley, 1990).

4.2.2 Social networks: size

In comparison to other published studies the social networks of the people with learning disabilities did not appear to be impoverished. The mean network size of 11.7 compares favourably with network sizes ranging from 3.1 in a British study of older people with learning disabilities (Dagnan & Ruddick, 1997) to 9.3 for older adults with learning disabilities living in a community residence (Krauss & Erickson, 1988). Higher network sizes have been reported in studies of adults without disabilities. Rosen and Burchard (1990) reported a mean network size of 17 for single adults without learning disabilities which was noted to be similar to other studies of the general population (Phillips & Fischer, 1981; Weinberg, 1984, both cited in Rosen & Burchard, 1990). Direct comparison between studies is not always possible because of different methodologies and use of different information sources. For example, Dagnan and Ruddick (1997) completed questionnaires in a group interview with key residential and day service staff, including the person with a learning disability "where possible". In contrast, the mother of the person with a learning disability provided all the data (other than level of disability) in the study by Krauss et al (1992). In their study a limit of 20 was placed on the number of individuals who could be named. Asking people with learning disabilities themselves about who was important in their lives and not placing any upper limit on the number of names could both have contributed

to the higher network size obtained in the present study. It is likely that family or staff in one setting will not know about the staff and friends who are important in other settings. This was borne out by the number of “don’t know” responses from informants on the Social Circles Questionnaire.

The size of the overall network for the physical disability group was more than twice that of the learning disability group. Data on network size for other groups of people with physical disabilities appears lacking in the literature. There are also few studies that compare different groups in the same study. One of the few studies to do so used a comparison group of adults without disabilities, matched for marital status, sex, age, and community size (Rosen & Burchard, 1990). In their study Rosen & Burchard (1990) also found that the comparison group had a network twice the size of that of the learning disability group. It would appear that the physical disability group were more similar to a non-disabled population than to people with learning disabilities.

The physical disability group differed from the learning disability group in terms of marital status (all of the learning disability group were single) and children. Neither group were asked directly about children although several of the physical disability group included their children in the circles, in which case the children were defined as members of their immediate family. It was assumed (because no children were mentioned) that none of the learning disability group had children with whom they were in contact. Spouses were

usually defined as “partners” although in more than one case the person was separated and had a new partner.

4.2.3 Social networks: composition

It could be argued that the learning disability group would be expected to nominate fewer network members because of their more limited intellectual abilities impacting on their memory and recall of names. However deficits in cognitive functioning do not provide a sufficient explanation for the differences between the target and comparison groups. The learning disability group were able to name a similar number of staff and friends with disabilities as the physical disability group (both groups attended day facilities where they had contact with other people with disabilities and with staff). The difference was in the proportion of friends without disabilities that made up the majority of the network for the physical disability group. For those with a learning disability, the majority of the network was made up of family members, friends with learning disabilities and staff; the identification of individuals without disabilities in social networks who were neither family nor staff was infrequent, as found by Rosen & Burchard (1990).

4.2.4 Social support: self-rated

As far as provision of functional support was concerned participants with a learning disability most frequently cited members of staff whereas those with a physical disability cited friends and family. One finding that was of interest but not easily quantifiable was the difficulty that some participants in both

groups had in giving more than one name for each of the questions about support (the FSI administration instructions state that respondents can name up to three people per question). Some of the participants with physical disabilities were apologetic when they could not think of anyone apart from a spouse or a part-time carer who they could turn to in time of need. In common with the findings of Felton & Berry (1992) groups (such as “the social club”) were nominated as well as individuals but on further questioning most participants in both groups were also able to give an individual name.

Self-rated social support amongst the learning disability group was very similar to a North American sample (Lunsky, 1997) for all social support sources other than Family. Participants in the present study rated their family more highly in terms of social support. The North American sample of 41 men and 43 women were of a similar age (mean 38 years, *SD* 10.4, range 20 to 65 years) and ability (mild mental retardation), however all of them were in supported living and none was living with family members.

Despite the discrepancies between the learning disability and comparison groups in terms of the size and composition of their social networks, perceptions of social support appeared to be little different. The only significant finding was of a perception of greater social support received from family members of those with a physical disability. One explanation for the few apparent differences is that people with learning disabilities see their relationships in a more positive light while the people with a physical disability

perceive their situation more realistically, thereby hiding expected differences. Interestingly Rosen & Burchard (1990) found that neither network size nor composition was related to well-being. Their participants with learning disabilities were no less satisfied with the amount of contact with network members or the supportiveness of these relationships than the participants without disabilities. The tendency of people with learning disabilities to see their relationships in a positive light has been the subject of recent research conducted by Lunsky & Benson (in press). They asked people with learning disabilities to rate video vignettes of supportive, non-supportive and ambiguous situations and found a positive bias in how they interpreted relationships compared to staff and community members. The ratings of videos were also found to predict participants' ratings of their own relationships (Lunsky & Benson, in press).

4.2.5 Social support: informant-rated

Informant-rated social support was also compared with the North American sample. The lower ratings for all support sources other than family, where no difference was found, may have been the result of differences between the informant groups. Informants in the present study were a mixed group of mainly parents and care staff. Parents or other close relatives made up 40 percent of the informants in the present study but only 17 percent in the study by Lunsky & Benson (1999).

Analysis of informant-rated social support was complicated by the lack of complete information, discussed above, which reduced the numbers of valid cases. This may be symptomatic of the way many people with learning disabilities have lives that are compartmentalised. Segregation of day services restricts the opportunities for making relationships that can be extended outside the day service setting (Firth & Rapley, 1990). Few of the participants spoke about relationships that cut across more than one setting, for example, friends who visited the family home.

Comparison of informant-rated and self-rated social support revealed a similar pattern of ratings with the highest ratings being given for staff support and the lowest for partner support. It was expected that informant- and self-rated social support would be positively correlated adding weight to the reliability and validity of the measures completed by participants. However the only significant correlation was for reciprocity of support. In this respect the present study fails to replicate the findings of Lunsky & Benson (1997) who reported correlations for all sources of support other than staff support. One explanation (in addition to the impact of missing values for the informant-rated social support) may be that in the Lunsky & Benson (1997) study the scoring of the SSSR was on a slightly different basis and included the number of supports people listed (Lunsky, personal communication).

This absence of correlation begs the question of whose report is the more valid – the informants, all of whom knew their participant, or the participants

themselves. Differences in the interpretation of relationships may well be significant here. The false perceptions and misinterpretations on the part of both people with learning disabilities and their carers described by Green & Schleien (1991, cited in Green et al 1995) may have occurred, whereby “facades of friendship” were taken as “true friend” experiences. Similar processes could have been involved in the interpretation of the range of support relationships, for example with staff, who may be perceived as a close friend by the person with a learning disability but just doing their job by the family carer. The answer to the earlier question of whose report is the most valid may be that both are equally valid – but the differences in perceptions of the two groups need to be recognised.

Many of the published studies on social support and people with learning disabilities rely solely on the report of third parties (Prosser & Moss, 1996; Grant, 1993). It may be easier to do so and indeed may be the only realistic approach when participants have severe or profound learning disabilities or severe communication problems. In recent years however cogent arguments have been raised in favour of far greater participation in research on the part of people with learning disabilities (McCarthy, 1998; Kiernan, 1999). One way of ensuring a consensus view of social support might be to use a group interview, which enables information to be gathered from more than one source at one point in time. Kennedy, Horner & Newton (1990) for example, included the participant with a learning disability and two people without disabilities, who knew the person concerned very well, in a single interview.

However the authors provided no information on how any differences in opinions were resolved.

4.2.6 Understanding of relationships

The small sub-group of six men and women were able to give some further insight into the meaning of different kinds of relationship experienced by people with learning disabilities. Between them they demonstrated a broad understanding of friendship and the characteristics of a friend that were important to them. The themes identified were similar to those that have been identified as important for the general population. Thus the group spoke about friends sharing activities, being supportive, understanding, likeable and trustworthy, all of which appeared in the ten most common characteristics of an ideal close friend described by a large American sample (Weiss & Lowenthal, 1975, cited in Cramer, 1998). One of the group described a relationship with another person with a learning disability who was physically disabled and much more dependent than himself as follows:

...he's my really good mate, my really good mate. And he knows when I come in because he always smiles at me, but he can't talk...it's just nice to talk to him.

Whilst similar characteristics were ascribed to relationships with a boy or girlfriend as to friends, the participants were clearly able to distinguish between friendship and a romantic relationship. The relationship with a boy or

girlfriend was characterised as being closer and involving love. Many people in the general population believe that love is one of the most desirable characteristics in choosing a mate (Cramer, 1998). All of the sub-group had had a boy or girlfriend at some point in their lives and most agreed that it was important to have a partner. As one of the women said, boyfriends were seen as important "cause they make you happy. Makes you happy to do things with them".

All but one of the group described their own experiences of intimate relationships or gave examples of other very close relationships when the meaning of the terms was given. The theme "impact of lack of close relationships" occurred in all of the transcripts with emotions such as sadness and anger being described more frequently than loneliness.

There was some evidence of a lack of awareness of boundaries in relationships with staff. The theme "perception of staff as close friends" occurred in two transcripts.

None of the questions on the interview schedule specifically addressed the issue of relationship breakdown but several of the participants described the pain and emotional consequences of relationships that had gone badly.

Despite the difficulty some of the participants had at times in finding the right words to express themselves, the depth of feeling that emerged was evident.

One described her feelings in the following way:

'I feel a bit, bit pulled downhill'

'I know what I'm going through, emotions and business.'

Another theme was "betrayal of trust" and related to the loss of trust that followed the break up of a relationship. As one of the women said:

'Then things went wrong with the lies, the stories.'

'I won't be able to trust him again.'

The theme "implied sexual pressure" was also identified:

'...like children, I goes no, no way. But he said we can try but no, oh no I don't feel like it...he was very annoyed with me, really very annoyed...I said whose body is it, is it mine or yours? Mine.'

'...I don't want that. I said 'stop R, I don't want it, I'm not, I got somebody else...she was kiss - kissing me...she was like, carrying on, you know, so I got my own girlfriend now.'

Women with learning disabilities vividly described the exploitative sexual relationships they had endured in a recent study by M.McCarthy (1999). In the present study it was not only the women who felt under this kind of pressure.

The negative impact of relationships was compounded by the lack of control participants had over their lives. Segregated services and lack of transport made it hard to maintain relationships outside the service setting. Most romantic relationships were with people who attended the same day centre and the same social clubs. If the relationship then broke down they would inevitably continue to see the person concerned on a regular basis. Unlike many of the general population few people with learning disabilities are in the position of being able to choose not to see someone.

4.3 Implications of the research

4.3.1 Implications for clinical practice

Although the lives of people with learning disabilities were characterised by participation in a range of valued experiences and activities, there was evidence of less social integration. Adopting the distinction made by Haring (1991, cited in Harris, 1995), the participants with learning disabilities were functionally integrated but not socially integrated. Functional integration refers to living, working, studying or enjoying leisure within the community whereas social integration implies fully participating in social interaction with a social network which includes casual and more intimate friends and relationships (Harris, 1995). Service providers need to be aware of the importance of developing social networks and encouraging supportive relationships. There is a role for the clinical psychologist in providing staff training or consultancy to raise awareness of these issues.

The model proposed by Firth & Rapley (1990) is helpful in conceptualising ways of achieving a richer social life and improved personal relationships. Firth & Rapley (1990) defined acquaintances as the people one is getting to know and argued that friendship usually develops out of acquaintance. It would follow that in order to develop a range of friendships and other non-kin relationships, there first need to be opportunities to make acquaintances. However increasing opportunities for social contact have not been sufficient of themselves in developing new and enduring relationships. The important factors are the quality of the opportunity and the likelihood of being able to participate in truly shared activities and experiences with a range of people.

There is a need for clinicians to develop innovative ways of improving interpersonal skills among people with learning disabilities. Individual or group work could usefully include elements such as the importance of first impressions, building self-esteem and the ability to understand other people's needs. The issues involved are complex and interventions likely to be long term.

The experiences of the small sub-group suggested that, just as for the normal population, relationships could often go badly. However people with learning disabilities are likely to be particularly vulnerable to emotional and psychological distress when the necessary social support is lacking. Carers and service providers need to be made aware of the possible consequences

of problems with relationships and accord them due seriousness. Referrals for psychological therapy or counselling may be appropriate.

Difficulties in relationships and problems arising from limited social support may also underlie or contribute to presenting problems such as depression or challenging behaviour. Clinicians need to be alert to the wider context of their clients' lives and recognise that their perception of social support may not match reality. The importance of adequate social networks and social support should not be underestimated.

4.3.2 Implications for future research

The present study was largely exploratory in its aims. Further research with a larger sample is needed to address the impact of important factors such as gender, residence and ability level. The issue of discrepancies between the perceptions of the people with learning disabilities and their carers is also worthy of further investigation. The verification of the support network could be pursued, for example, by involving some of the key network members in providing additional information.

Further research is also needed to look at other groups of people with learning disabilities. The most able people with learning disabilities increasingly live in supported living situations and have minimal, if any, contact with day centres. Such people could be particularly vulnerable if they are not well socially integrated.

The present study confirmed the value of people with mild or moderate learning disabilities participating in research. Involving people with more severe disabilities presents a challenge for future research in this area.

4.4 Conclusion

The research described has endeavoured to explore the nature and significance of social support and close relationships amongst a group of people with learning disabilities and a comparison group of people with physical disabilities. The learning disability group were found to enjoy a greater number of valued life experiences than expected both in comparison with people with other disabilities and the general population. However the people with learning disabilities were found to be significantly worse off in the sphere of relationships, with smaller networks and a more limited range of support sources.

In describing their own relationships it was evident that people with learning disabilities experience the joys and heartaches in much the same way as anyone else, yet may lack many of the skills and resources others take for granted.

It was concluded that whilst people with learning disabilities have become increasingly well functionally integrated (living, working and being in the

community) the majority have yet to become truly socially integrated and remain, in the words of Myers et al (1998) “outside looking in” (p. 393).

BEST COPY

AVAILABLE

Variable print quality

REFERENCES

Ager, A.K. (1998). The BILD Life Experiences Checklist. Kidderminster: BILD.

Ager, A.K., Annetts, S., Barlow, R., Copeland, C., Kemp, L., Sacco, C. & Richardson, S.A. (1988). Life experiences and quality of life in the general population: a study of Leicester and its environs using the Life Experiences Checklist. Mental Handicap Research Group Working Paper 2 (Revised), Leicester: University of Leicester Department of Psychology.

Arcsott, K., Dagnan, D. & Stenfert Kroese, B. (1998). Consent to psychological research by people with an intellectual disability. Journal of Applied Research in Intellectual Disabilities, 11, 1, 77-83.

Alloway, R. & Bebbington, P. (1987). The buffer theory of social support - a review of the literature. Psychological Medicine, 17, 91-108.

Antaki, C. & Rapley, M. (1996). Questions and answers to psychological assessment schedules: hidden troubles in 'quality of life' interviews. Journal of Intellectual Disability Research, 40, 5, 421-437.

Antonucci, T.C. & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. Journal of Gerontology, 42, 5, 519-527.

Barber, D. & Hupp, S.C. (1993). A comparison of friendship patterns of individuals with developmental disabilities. Education and Training in Mental Retardation and Developmental Disabilities, 28, 1, 13-22.

Bolton, W. & Oatley, K. (1987). A longitudinal study of social support and depression in unemployed men. Psychological Medicine, 17, 453-460.

Booth, T. & Booth, W. (1994). Parenting Under Pressure. Buckingham: Open University Press.

Bowlby, J. (1971). Attachment and Loss: I : Attachment. Harmondsworth: Penguin.

Bowling, A. (1997). Measuring Health: A Review of Quality of Life Measurement Scales. Buckingham: Open University Press.

Boyatzis, R.E. (1998). Transforming Qualitative Information: Thematic Analysis and Code Development. London: Sage.

- Broman, C.L. (1993). Social relationships and health-related behaviour. Journal of Behavioural Medicine, 16, 4, 335-350.
- Brown, G.W. & Harris, T. (1978). Social Origins of Depression. London: Tavistock.
- Bukowski, W.M., Newcomb, A.F. & Hartup, W.W. (1996). The Friendship they Keep: Friendship in Childhood and Adolescence. Cambridge: Cambridge University Press.
- Chappell, A.L. (1994). A question of friendship: community care and the relationships of people with learning difficulties. Disability and Society, 9, 4, 419-434.
- Clare, I.C.H. & Gudjonsson, G.H. (1995). The vulnerability of suspects with intellectual disabilities during police interviews: A review and experimental study of decision-making. Mental Handicap Research, 8, 2, 110-128.
- Clegg, J.A. & Standen, P.J. (1991). Friendship among adults who have developmental disabilities. American Journal on Mental Retardation, 95, 6, 663-671.
- Cohen, S. & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98, 310-357.
- Cooley, C.H. (1909). Social Organisation: a Study of the Larger Mind. New York: C. Scribner's Sons.
- Coyne, J.C. & Downey, G. (1991). Social factors and psychopathology: stress, social support, and coping processes. Annual Review of Psychology, 42, 401-425.
- Cramer, D. (1998). Close Relationships: The Study of Love and Friendship. New York: Arnold.
- Dagnan, D. & Ruddick, L. (1997). The social networks of older people with learning disabilities living in staffed community based homes. The British Journal of Developmental Disabilities, 43, 1, 43-53.
- Duck, S. (1990). Relationships as unfinished business: out of the frying pan and into the 1990s. Journal of Social and Personal Relationships, 7, 5-28.
- Duck, S. (1995). Repelling the study of attraction. The Psychologist, 8, 60-63

Duck, S. (1999). Relating to Others, 2nd ed. Buckingham: Open University Press.

Duck, S. & Miell, D. (1986). Charting the development of personal relationships. In R. Gilmour & S. Duck (Eds), The Emerging Field of Personal Relationships, pp 133-143. Hillsdale: Erlbaum.

Durkheim, E. (1951). Suicide: A Study in Sociology. Trans. J.A. Spaulding & G. Simpson. New York: Free Press.

Edgerton, R.B. (1967). The Cloak of Competence: Stigma in the Lives of the Mentally Retarded. Berkeley: University of California Press.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. British Journal of Clinical Psychology, 38, 215-219.

Feingold, A. (1992). Good looking people are not what we think. Psychological Bulletin, 111, 304-341.

Felton, B.J. & Berry, C. (1992). Groups as social network members: overlooked sources of social support. American Journal of Community Psychology, 20, 2, 253-261.

Finlay, W.M.L. & Lyons, E. (2000). Methodological issues in interviewing and using self-report scales with people with mental retardation. Unpublished manuscript, School of Human Sciences, University of Surrey.

Firth, H. & Rapley, M. (1990). From Acquaintance to Friendship. Issues for People with Learning Disabilities. Clevedon: BIMH.

Flaherty, J.A., Gaviria, F.M. & Pathak, D.S. (1983). The measurement of social support: the social support network inventory. Comprehensive Psychiatry 24, 6, 521-529.

Flynn, M.C. (1989). Independent Living for Adults with Mental Handicap: "A Place of my Own". London: Cassell Educational.

Gottlieb, B.H. (1983). Social Support Strategies: Guidelines for Mental Health Practice. Beverley Hills: Sage.

Grant, G. (1993). Support networks and transitions over two years among adults with a mental handicap. Mental Handicap Research, 6, 1, 37-55.

Gratton, C. (1999). Gender and Women with Learning Disabilities. D. Clin. Psych. Thesis: Canterbury Christ Church University College.

Green, F.P., Schleien, S.J., Mactavish, J. & Benepe, S. (1995). Nondisabled adults' perceptions of relationships in the early stages of arranged partnerships with peers with mental retardation. Education and Training in Mental Retardation and Developmental Disabilities, June, 91-108.

Hammersley, M. (1996). The relationship between qualitative and quantitative research: paradigm loyalty versus methodological eclecticism. In J.T.E. Richardson (Ed.), Handbook of Qualitative Research Methods for Psychology and the Social Sciences, pp 159-174 Leicester: BPS Books.

Harris, P. (1995). Who am I? Concepts of disability and their implications for people with learning difficulties. Disability and Society, 10, 3, 341-351.

Harter, S. (1985). "People in my Life" Social Support Scale for Children. Denver: University of Denver.

Hazan, C. & Shaver, P. (1987). Romantic love conceptualised as an attachment process. Journal of Personality and Social Psychology, 52, 511-524.

Henwood, K.L. & Pidgeon, N.F. (1992). Qualitative research and psychological theorizing. British Journal of Psychology, 83, 97-111.

Homans, G.C. (1961). Social Behaviour: Its Elementary Forms. New York: Harcourt, Brace & World.

Hughes, A., McAuslane, L. & Schur, H. (1996). Comparing quality of life for people with learning disabilities and people who are unemployed or retired. British Journal of Learning Disabilities, 24, 99-103.

Kahn, R.L. & Antonucci, T.C. (1980). Convoys over the life course: attachment, roles and social support. In P.B. Baltes & O.G. Brim (Eds), Life Span Development and Behaviour, pp 253-286 New York: Academic Press.

Kennedy, C.H., Horner, R.H. & Newton, J.S. (1989). Social contacts of adults with severe mental retardation living in the community: A descriptive analysis of relationship patterns. Journal of the Association for Persons with Severe Handicaps, 14, 190-196.

Kennedy, C.H., Horner, R.H. & Newton, J.S. (1990). The social networks and activity patterns of adults with severe mental retardation: A correlational analysis. Journal of the Association for Persons with Severe Handicaps, 15, 86-90.

- Kiernan, C. (1999). Participation in research by people with learning disability: origins and issues. British Journal of Learning Disabilities, 27, 43-47.
- Kinnear, P.R. & Gray, C.D. (1999). SPSS for Windows Made Simple (Third Edition). Hove: Psychology Press
- Krauss, M.W. & Erickson, M. (1988). Informal support networks among persons with mental retardation: a pilot study. Mental Retardation, 26, 4, 197-201.
- Krauss, M.W., Seltzer, M.M. & Goodman, S.J. (1992). Social support networks of adults with mental retardation who live at home. American Journal on Mental Retardation, 96, 4, 432-441.
- Krippendorff, K. (1980). Content Analysis: An Introduction to its Methodology. London: Sage.
- Langlois, J.H. & Roggman, L.A. (1990). Attractive faces are only average. Psychological Science, 1, 115-121.
- Lin, N., Woelfel, M. & Light, S.W. (1986). Buffering the impact of the most important life event. In N. Lin., A. Dean & W.M. Ensel (Eds) Social Support, Life Events and Depression. New York: Academic Press.
- Luckasson, R., Coulter, D.L., Polloway, E.A., Reiss, S., Schalock, R.S., Snell, M.E., Spitalnik, D.M. & Stark, J.A. (1992). Mental Retardation: Definition, Classification, and System of Supports. Washington: American Association on Mental Retardation.
- Lunsky, Y. (1997). Social support as a predictor of well-being for adults with mental retardation. PhD thesis, Ohio State University.
- Lunsky, Y. & Benson, B.A. (1997). Reliability of ratings of consumers with mental retardation and their staff on multiple measures of social support. American Journal on Mental Retardation, 102, 3, 280-284.
- Lunsky, Y. & Benson, B.A. (1999). Social circles of adults with mental retardation as viewed by their caregivers. Journal of Developmental and Physical Disabilities, 11, 2, 115-129.
- Lunsky, Y. & Benson, B.A. (in press). Perceived social support and mental retardation: a social-cognitive approach. Cognitive Therapy and Research.
- Lunsky, Y. & Haverkamp, S.M. (1999). Distinguishing low levels of social support and social strain: implications for dual diagnosis. American Journal on Mental Retardation, 104, 2, 200-204.

Lutfiyya, A.M. (1991). "A feeling of being connected": Friendships between people with and without learning difficulties. Disability, Handicap and Society, 6, 3, 233-245.

McCarthy, G. (1999). Attachment style and adult love relationships and friendships: a study of a group of women at risk of experiencing relationship difficulties. British Journal of Medical Psychology, 72, 305-321.

McCarthy, M. (1998). Interviewing people with learning disabilities about sensitive topics: A discussion of ethical issues. British Journal of Learning Disabilities, 26, 140-145.

McCarthy, M. (1999). Sexuality and Women with Learning Disabilities. London: Jessica Kingsley.

McColl, M.A. & Skinner, H. (1995). Assessing inter- and intrapersonal resources: social support and coping among adults with a disability. Disability and Rehabilitation, 17, 1, 24-34.

McDowell, I. & Newell, C. (1996). Measuring Health: A Guide to Rating Scales and Questionnaires, 2nd ed. Oxford: Oxford University Press.

Meins, W. (1993). Prevalence and risk factors for depressive disorders in adults with intellectual disability. Australia and New Zealand Journal of Developmental Disabilities, 18, 3, 147-156.

Myers, F., Ager, A., Kerr, P & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. Disability and Society, 13, 3, 389-413.

Newton, J.S., Horner, R.H., Ard, Jr., W.R., LeBaron & Sappington, G. (1994). A conceptual model for improving the social life of individuals with mental retardation. Mental Retardation, 32, 6, 393-402.

Newton, J.S., Olson, D. & Horner, R.H. (1995). Factors contributing to the stability of social relationships between individuals with mental retardation and other community members. Mental Retardation, 33, 6, 383-393.

Nezu, C.M., Nezu, A.M., Rothenberg, J.L., DelliCarpini, L. & Groag, I. (1995). Depression in adults with mild mental retardation: are cognitive variables involved? Cognitive Therapy and Research 19, 2, 227-239.

Oppenheim, A.N. (1992). Questionnaire Design, Interviewing and Attitude Measurement, new ed. London: Pinter.

Parker, R., Sprague, J., Flannery, K.B., Niess, J. & Zumwait, L. (1991). Measuring the social perceptions of persons with moderate and severe disabilities to construct social network maps. Journal of Developmental and Physical Disabilities, 3, 1, 23-45.

Pidgeon, N. (1996). Grounded theory: theoretical background. In J.T.E. Richardson (Ed.), Handbook of Qualitative Research Methods for Psychology and the Social Sciences. pp 75-85. Leicester: BPS Books.

Prosser, H. & Bromley, J. (1998). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds), Clinical Psychology and People with Intellectual Disabilities, pp 99-113 Chichester: Wiley.

Prosser, H. & Moss, S. (1996). Informal care networks of older adults with an intellectual disability. Journal of Applied Research in Intellectual Disabilities, 9, 1, 17-30.

Redfern, S.J. & Norman, I.J. (1994). Validity through triangulation. Nurse Researcher, 2, 2, 41-56.

Reiss, S. & Benson, B.A. (1985). Psychosocial correlates of depression in mentally retarded adults: I. Minimal social support and stigmatization. American Journal on Mental Retardation, 89, 4, 331-337.

Rodgers, J. (1999). Trying to get it right: undertaking research involving people with learning difficulties. Disability and Society, 14, 4, 421-433.

Rosen, J.W. & Burchard, S.N. (1990). Community activities and social support networks: a social comparison of adults with and adults without mental retardation. Education and Training in Mental Retardation and Developmental Disabilities, 25, 193-204.

Rubin, Z. (1973). Liking and Loving: An Invitation to Social Psychology. New York: Holt, Rinehart & Winston.

Sands, D.J. & Kozleski, E.B. (1994). Quality of life differences between adults with and without disabilities. Education and Training in Mental Retardation and Developmental Disabilities, 90-101.

Sarason, B.R., Pierce, G.R. & Sarason, I.G. (1990). Social support: the sense of acceptance and the role of relationships. In B.R. Sarason, I.R. Sarason & G.R. Pierce (Eds), Social Support: An Interactional View. New York: Wiley.

Secord, P.F. & Backman, C.W. (1974). Social Psychology, 2nd ed. Tokyo: McGraw-Hill Kogalusha.

Sigelman, C.K., Budd, E.C., Spanhel, C. L. & Schoenrock, C.J. (1981). When in doubt say yes: Acquiescence in interviews with mentally retarded persons. Mental Retardation, 19, 53-58.

Sigelman, C.K., Budd, E.C., Winer, J.L., Schoenrock, C.J. & Martin, P.W. (1982). Evaluating alternative techniques of questioning mentally retarded persons. American Journal of Mental Deficiency, 85, 5, 511-518.

Silverman, D. (1993). Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction. London: Sage.

Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith, R. Harre & L. Van Langenhove (Eds), Rethinking Methods in Psychology. London: Sage.

Taylor, S.J. & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: towards an understanding of acceptance. Disability, Handicap and Society, 4, 1, 21-36.

Thibaut, J.W. & Kelley, H.H. (1959). The Social Psychology of Groups. New York: Wiley.

Tindall, C. (1994). Issues of evaluation. In P. Banister, E. Burman, I. Parker, M. Taylor & C. Tindall, Qualitative Methods in Psychology: A Research Guide. Buckingham: Open University Press.

Turnbull, A.P., Pereira, L. & Blue-Banning, M.J. (1999). Parents' facilitation of friendships between their children with a disability and friends without a disability. Journal of the Association for Persons with Severe Handicaps, 24, 2, 85-99.

Turpin, G., Barley, V., Beail, N., Scaife, J., Smith, J.A. & Walsh, S. (1997). Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. Clinical Psychology Forum, 108, 03-Jul.

Winch, R.F. (1958). Mate-selection: A Study of Complementary Needs. New York: Harper & Brothers.

Wolfensberger, W. (1972). The Principles of Normalisation in Human Services. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1983). Social role valorisation: a proposed new term for the principle of normalisation. Mental Retardation, 21, 234-239.

Wright, P.H. (1984). Self-referent motivation and the intrinsic quality of friendship. cited in Clegg & Standen, 1991 Journal of Social and Personal Relationships, 1, 115-130.

Ethical approval

Mrs
Ethics Committee Co-ordinator
LREC

22 December 1999

Dear Mrs

The significance of social support and close relationships for people with learning disabilities.

Please find enclosed a revised submission of my application for ethics approval of the above study.

I have discussed the points that were made by the committee at the meeting on 20 October with Dr Jan Burns, academic supervisor at Salomons, and with Rachel Churchill at St George's Hospital RDSU. Although I have dealt with all the points in the body of the revised application and research proposal I thought it would be helpful for the committee if I provided further explanation for some of the points as follows:

1. How will the control group be recruited?

I have been advised that the physical disability group would be better described as a comparison group. This is an observational study with a subject group of interest and a comparison group. The method of recruitment will be similar for both groups in order to limit selection bias. In both cases the initial contact will be made with the manager of the day centre or day service who will identify potential participants who meet the inclusion criteria. The manager will give out the PIS and consent form to potential participants. I will only be given the names of participants once they have given their consent, at which point I would be able to approach them individually.

2. What support services have you identified that will be available for both the intervention group and the control group e.g. counselling?

This point is addressed in the answer to question 30 on the application form.

3. What mechanisms are in place should you identify physical or sexual abuse in either the intervention or control group?

This point has also been addressed in the answer to question 30. NHS Trust has a policy entitled "Abuse of Vulnerable Adults" which includes guidelines on recognition of abuse, how to respond to disclosure, confidentiality i.e. who needs to know and when confidentiality should be breached etc. The policy would be followed if abuse were identified.

4. Patient Information Sheet (PIS)

a) What is the readability score considering the focus is on those with special needs?

Learning disability group: Flesch Index 77.9; Flesch-Kincaid grade level 6.6
Carer (informant) group: Flesch Index 74.9; Flesch-Kincaid grade level 6.5
Physical disability group: Flesch Index 77.2; Flesch-Kincaid grade level 6.4

As far as the learning disability group is concerned I will not be relying solely on the ease with which the PIS might be read as many people with learning disabilities have very limited reading ability. The information sheet will also be read aloud and given to carers.

b) Are there separate PIS for control group and carers?

Yes, these are included with the application.

c) What is the time interval between information and consent?

My intention is to give people a few days between having the information and giving consent in order that they have the opportunity to discuss it with other people if they want to but can still recall the information.

d) You may need to explain why you wish to record or write everything down as they may not understand the need for this?

I intend to explain to the learning disability group that I need to keep a record of what is said so that I can look at it afterwards and see how lots of people answer the questions. Tape recording will only be required for the sub-group of 5 to 6 participants who will be followed up.

5. Have you considered the ethical implications of establishing a problem within the control group i.e. people with physical disabilities. What facilities/agreements have you got available to deal with potential problems in the control group?

I think this is covered by my answers to points 2 and 3.

6. *What is the study endpoint e.g. how is this information going to help them, how is it going to be used?*

This point is addressed in the answer to question 5 on the application form.

7. *The committee thought the number of questionnaires could be onerous and confusing for participants.*

I have dropped two of the questionnaires. For the remainder I have provided a table on a separate sheet to clarify which questionnaires are for each group, how they will be administered and estimation (based on pilot work and previous knowledge) of the length of time required. Assessment using standardised tests and measures is a key part of the role of a clinical psychologist in learning disabilities and I would expect to exercise my experience and clinical judgement in recognising when and if the procedure is causing any stress.

8. *The committee thought the question "Do you have any staff?" on the Social Support questionnaire could be interpreted differently by different people.*

This is a helpful comment and I have amended the question to "Is anyone employed to care for you?".

9. *The research question has 4 parts and is considered too broad to obtain meaningful results. The committee suggest a better qualitative project would result if you omitted part 2 of your research question.*

The scope of the research has been narrowed and no longer includes reference to self-concept. However the comparison group has been retained as the external examiner to the doctorate course advised its inclusion. I have attempted to explain the research design in more detail in my research proposal. I would argue that the inclusion of the physical disability group is not for the purposes of control but rather to add qualitative depth to an exploratory study.

I have also submitted an application to the LREC in order to be confident of achieving a sufficiently large enough sample. I am awaiting their written feedback. I would appreciate your advice as to how to co-ordinate the two submissions in order to end up with a single research project that meets the requirements of both committees.

Yours sincerely

Tessa Lippold

13 January 2000

Dear Mr

The significance of social support and close relationships for people with learning disabilities.

Please find enclosed a revised submission of my application for ethics approval of the above study.

I have discussed the points that were made by the committee at the meeting on 7 December with Dr Jan Burns, academic supervisor at Salomons. Although I have dealt with all the points in the body of the revised application I thought it would be helpful for the committee if I provided further explanation for some of the points as follows:

1. The title and objectives of the study

I agree with the committee that the use of the word "sexuality" in the title was misleading and I have therefore dropped it. As the research project has evolved I have moved away from an earlier intention to cover sexuality more specifically. I have also clarified my objectives in section 3 of the application form to reflect the fact that the primary focus is on people with learning disabilities.

2. The inclusion/exclusion criteria does not define the level of physical disability.

I have answered this point in section 8 on the application form. I have deliberately kept the categories of disability fairly broad as I do not want to restrict numbers unnecessarily.

3. The day centre manager is not sufficiently independent. Consent form must be signed by an independent witness.

As far as recruitment into the study is concerned it is my intention to use the same method for both the learning disability and physical disability groups. The initial contact will be made with the day centre manager who will identify potential participants who meet the inclusion criteria. The manager will give out the information sheet and consent form and provide a verbal explanation to potential participants. I intend to enlist the assistance of one of the local advocacy groups

(such as Community Partners) to provide an independent person who can be present at the time the verbal explanation is given and also act as a witness to the signing of the consent form. In order to ensure confidentiality is maintained and that there is no coercion to consent I will only be given the names of participants once they have been through this process.

4. It is essential that GPs are involved.

I am happy to inform GPs with the permission of participants and have amended the consent form accordingly. I have also included a copy of a letter for the GP which would be sent together with the relevant information sheet.

5. The consent form must be explicit about the participant agreeing to the approach to, and interview of, the keyworker or carer.

The consent form has been amended.

6. The information sheet for subjects with learning disabilities does not mention that the study is making a comparison between the two study groups.

The information sheet has been amended.

7. The Life Experiences Checklist contains a space for name and address.

This has been removed from the form. Identification numbers only will be used on all checklists and questionnaires in order to maintain confidentiality. The use of the term "informant" is, I believe, standard practice in the literature when one person is responding on behalf of another whom they know well. The LEC is a standardised measure that has been widely used in clinical work and research, mostly with people with learning disabilities but also with a variety of other client groups.

8. The committee felt that the first question on page 2 of the checklist was difficult to understand. In addition the questionnaire is a very substantial document.

I am not aware that this question has caused any difficulty in other studies. However all the questionnaires will be completed during face-to-face interviews and obviously I would be able to clarify anything that participants found confusing. As far as the questionnaire is concerned I assume that this is a reference to the Social Circles Questionnaire, which is the lengthiest of the measures being used. This will be completed by one group, (the carers or keyworkers), all of whom will know the person with learning disabilities well. I have piloted the SCQ on a colleague (not a clinical psychologist) who completed it for a client she was working with in a residential setting and it took her less than

20 minutes. I have drawn up a table listing all of the measures, who they will be completed by and how long they take.

9. *The committee asked whether or not you are directly involved with the care of the subject group.*

It is possible that I may be directly involved with the care of a few of the subject group. However it is more likely that they will be unknown to me and may have no involvement with secondary or tertiary health care services. The recruitment procedure has been outlined under point 3 above.

I do hope I have now answered all the committee's concerns and that the application now meets your requirements.

Yours sincerely

Tessa Lippold

Our ref: SKT/jmc/ 117/B/12834

10 February 2000

Ms Tessa Lippold
Community Learning
Disability Team

Dear Ms Lippold

117/B – The significance of social support and close relationships for people with learning disabilities

Decision: Approved

Thank you for attending our meeting on 9 February 2000, to answer questions about your proposed research. Ethical approval is granted. However, I must emphasise that whilst the Committee look at work on ethical grounds, it is up to the Trust to finally sanction the work, taking into account financial and other implications.

At the meeting you informed us that ' LREC have also now approved the submission with the proviso that the GPs are informed. We have noted this as an agreed protocol amendment.

In line with good practice, a list of members at the February meeting is enclosed.

The documents reviewed were:

1. Application Form signed by dated 23 December 1999
2. Protocol – undated
3. Participant Information Sheet
4. Consent Form 763 4/98
5. Comparison Group Information Sheet 7.11.99 version 3/pd
6. Carers Information Sheet 7.11.99 version 3/carers

7. Student form signed by Dr Burns dated 24 December 1999
8. Grid of Measures
9. Circles Task
10. Social Support Self report
11. Functional Support interview
12. Social Circles Questionnaire
13. Life Experiences Check list
14. Semi-structured interview

The Committee wish you every success with your study. The following standard conditions apply to all our approvals:

- a). That you notify the LREC immediately of any information received or of which you become aware which would cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the LREC and/or which would raise questions about the safety and/or continued conduct of the research.
- b) It is the researcher's responsibility to comply with the latest Data Protection Act and Caldicott Guardian issues.
- c) You need to comply, throughout the conduct of the study, with good clinical research practice standards.
- d) Amendments need to be approved by the LREC.
- e) You must supply an annual summary of the progress of the research project and of the conclusion and outcome of the research project and inform the LREC should the research be discontinued.

Yours sincerely

LOCAL RESEARCH ETHICS COMMITTEE
Stamford Medical Centre

08 February 2000

Ms T Lippold

The significance of social support and close relationships for people with learning disabilities

I am please to inform you that at its meeting held on 25 January 2000 the Committee approved the above study.

The Committee's decision was based its review of:

- (i) Your letter to me dated 13 January 2000 responding to the Committee's comments on your original submission to it.
- (ii) The following documents enclosed with your letter of 13 January:
 - (a) The revised LREC Application form which you signed on 14 January 2000.
 - (b) The revised dissertation research proposal and research summary.
 - (c) The revised Consent Form.
 - (d) The revised Information Sheet for participants.
 - (e) The Information Sheet for carers.
 - (f) The Information Sheet for comparison group (physical disability).
 - (g) The summary of measures to be completed enclosing the Circles Task Document, Social Circles Questionnaire, Life Experiences Check list and Interview Schedule.

The Committee's approval is subject to the following conditions:

No deviations from or changes of the protocol should be initiated without prior written approval of the Committee.

The Committee should be provided with a copy of the report on the outcome of the study or a copy of any published document.

If the start of the project is delayed by more than one year from the date of approval the protocol should be resubmitted to the Committee for further review.

The Committee noticed that there was still a reference to "sexuality" in the documents. These should be removed.

Yours sincerely

Information sheets and letter to GP

Support and Relationships in Learning Disabilities

Information sheet for participants

You are invited to take part in some research.

Before you decide if you want to take part it is important to understand what this research is, why it is being done and what you will be asked to do.

Please listen carefully and then take this sheet away with you to read and discuss with other people such as staff, friends, family or your GP if you want to.

Ask me if there is anything that is unclear or if you want to know more about it.

Take time to decide if you want to take part or not.

What is research?

Doing research means finding out about something by reading, asking questions and talking to people.

When the research is finished it is usually written down so that other people can be told about it or read it themselves.

What is this research about? Why is it being done?

This research study is about what people with learning disabilities and people with physical disabilities think about relationships with their friends, family and other people they are close to.

It is also about how you spend your time with other people and some of the things you do together.

It is being done so that I can learn about what people with disabilities think about their lives and their experiences and help others to understand too.

Why have I been chosen to take part?

You were chosen because you attend a day centre for people with learning disabilities and also because you are good at talking to people.

Altogether 30 people with learning disabilities will be taking part, about half of them men and half women. The same number of people with physical disabilities will also be asked some of the same questions.

I will be asking each person with a learning disability if I could also talk to their carer or keyworker where they live.

Do I have to take part?

It is up to you whether to take part or not.

If you decide "yes" then I will give you this sheet to keep and give you a form to sign as well. If you say "yes", you can still change your mind whenever you want to and stop if you don't want to take part anymore.

It is okay to say "no" if you don't want to take part.

What will I have to do if I take part?

I will come and see you on your own either at the day centre or at your home. I will ask you some questions about you and your friends, who you are close to and what activities you do in your free time.

I will also ask your carer or keyworker to answer some questions. The questions will take less than an hour of your time.

I may also ask you later on to talk some more about people you are close to. If I do see you again I will ask you if what we say can be tape recorded, so that I don't have to write down everything you say.

What are the possible disadvantages and risks of taking part (bad things that could happen)?

You may miss part of a session at the day centre while you are talking to me.

You may find some of the questions are quite personal (but you don't have to answer all the questions if you don't want to).

You may find that some things we talk about make you think of something bad or upsetting that has happened to you. You don't have to talk about it if you don't want to. If you do want to talk about it I will make sure we have extra time or arrange another time to see you. Or I could arrange for you to see someone else for help if you want it.

What are the possible benefits of taking part (good things that could happen)?

I hope you will find it interesting. By talking to lots of people with learning disabilities it will help us all understand more about relationships and what is important. We will be better at helping people when they need it.

What about confidentiality?

Keeping things confidential means that I will not tell other people what you say and I will make sure that your name and address are not on anything I write down for other people.

I will also be talking to your carer or keyworker about what you do but not about what you say to me. The only time I may say something to anyone else is if you tell me something which might mean that you or another person is not safe.

Any tapes made will only be kept while the research is going on and once everything has been written down the recording will be destroyed.

What happens when the research study is finished?

Some of the information I get from talking to people like you will be written down so that other people can get to know what I have found out. However they will not know that you have taken part.

Thank you very much for your time.

Contact for further information:

Tessa Lippold

Tel:

Signed by the person in charge of the project.....

**TESSA LIPPOLD
CHARTERED CLINICAL PSYCHOLOGIST**

The Local Research Ethics Committee has approved the above statement.

13.01.00 version 4/ld

Support and Relationships in Learning Disabilities

Information sheet for comparison group (physical disability)

You are invited to take part in some research.

Before you decide if you want to take part it is important to understand what this research is, why it is being done and what you will be asked to do.

Please read this sheet carefully. You can take it away with you to read and discuss with other people such as staff, friends, family or your GP if you want to.

Ask me if there is anything that is unclear or if you want to know more about it.

Take time to decide if you want to take part or not.

What is this research about? Why is it being done?

This research study is about what people with disabilities think about relationships with their friends, family and other people they are close to.

It is also about how you spend your time with other people and some of the things you do together.

I am primarily interested in what people with learning disabilities think about relationships but I am also talking to some people like yourself who have a physical disability.

The research is being done so that I can learn about what people with disabilities think about their lives and their experiences and help others to understand too.

Why have I been chosen to take part?

You were chosen because you attend a centre for people with disabilities and also because you are good at talking to people.

Altogether 30 people with physical disabilities will be taking part, about half of them men and half women.

Do I have to take part?

It is up to you whether to take part or not.

If you decide "yes" then I will give you this sheet to keep and give you a form to sign as well. If you say "yes", you can still change your mind whenever you want to and stop if you don't want to take part anymore.

It is okay to say "no" if you don't want to take part.

What will I have to do if I take part?

I will come and see you on your own either at the centre or at your home. I will ask you some questions about you and your friends, who you are close to and what activities you do in your free time.

The questions will take about half an hour of your time.

What are the possible disadvantages and risks of taking part?

You may miss part of a session at the day centre while you are talking to me. You may find some of the questions are quite personal (but you don't have to answer all the questions if you don't want to).

You may find that some things we talk about make you think of something bad or upsetting that has happened to you. You don't have to talk about it if you don't want to. If you do want to talk about it I will make sure we have extra time or arrange another time to see you. Or I could arrange for you to see someone else for help if you want it.

What are the possible benefits of taking part?

I hope you will find it interesting. By talking to lots of people with disabilities it will help us all understand more about relationships and what is important.

We will be better at helping people when they need it.

What about confidentiality?

Your answers will remain anonymous and confidential. Keeping things confidential means that I will not tell other people what you say and I will make sure that your name and address are not on anything I write down for other people.

What happens when the research study is finished?

Some of the information I get from talking to people like yourself will be written down so that other people can get to know what I have found out. However they will not know that you have taken part.

Thank you very much for your time.

**Contact for further information:
Tessa Lippold
Tel:**

7.11.99 version 3/pd

Support and Relationships in Learning Disabilities

Information sheet for carers

_____ has agreed to take part in some research and will be answering some questions on support and relationships. He/she has also nominated you to complete a couple of questionnaires on their behalf.

Before you decide if you want to take part it is important to understand what this research is, why it is being done and what you will be asked to do.

Please read this sheet carefully. You can take it away with you to read and discuss with other people such as staff, friends, family or your GP if you want to. You may also have a copy of the information sheet for participants with learning disabilities if you like.

Ask me if there is anything that is unclear or if you want to know more.

Take time to decide if you want to take part or not.

What is this research about? Why is it being done?

This research study is about what people with learning disabilities think about relationships with their friends, family and other people they are close to.

It is also about how they spend time with other people and some of the things they do together.

It is being done so that I can learn about what people with learning disabilities think about their lives and their experiences and help others to understand too.

Why have I been chosen to take part?

You were chosen by the person with a learning disability because you know them well.

Altogether 30 people with learning disabilities will be taking part, about half of them men and half women. For each of them I will also be talking to their keyworker, family carer, or other familiar person.

Do I have to take part?

It is up to you whether to take part or not.

If you decide "yes" then I will give you this sheet to keep and give you a form to sign as well. If you say "yes", you can still change your mind whenever you want to and stop if you don't want to take part anymore.

It is okay to say "no" if you don't want to take part.

What will I have to do if I take part?

I will arrange to see you at your convenience. I will ask you to complete two questionnaires about the person with a learning disability, their friends and who they are close to and what sorts of things they do together. The questions will take about half an hour.

What are the possible disadvantages and risks of taking part?

It will take up some of your time.

What are the possible benefits of taking part?

I hope you will find it interesting. By talking to lots of people with learning disabilities and their carers it will help us all understand more about relationships and what is important. We will be better at helping people when they need it.

What about confidentiality?

Your answers will remain anonymous and confidential. Keeping things confidential means that I will not tell other people what you say and I will

make sure that your name and address are not on anything I write down for other people.

What happens when the research study is finished?

Some of the information I get from talking to people like yourself will be written down so that other people can get to know what I have found out.

However they will not know that you have taken part.

Thank you very much for your time.

Contact for further information:

Tessa Lippold

Tel:

7.11.99 version 3/carer

Dear Dr

The significance of social support and close relationships for people with learning disabilities.

I am conducting a research study as part of a post qualification Doctorate in Clinical Psychology. I shall be exploring the nature of social support amongst people with learning disabilities, looking at how this compares with people with other disabilities and finding out from those with learning disabilities what they think about the different kinds of relationships they experience in their lives.

The research will involve interviewing people with learning disabilities and their carer using a number of questionnaire measures. For comparison purposes I will be using some of the same measures with a group of people with physical disabilities.

One of the people who has given their consent to participate in the study is a patient of yours. He/she has agreed for you to be notified and to release information about relevant medical history.

Name and date of birth

Address

The study has been approved by _____ Local Research Ethics Committee who require that you are informed. Please advise me if you are aware of your patient being involved in any other research that might affect this study.

I enclose an information sheet, do let me know if you would like any additional information.

Yours sincerely

Tessa Lippold
Chartered Clinical Psychologist

Consent forms

CONSENT FORM

Title of project: **Support and Relationships in Learning Disabilities**

Name of researcher: **Tessa Lippold**

I have read the information sheet dated 13.01.00 and I understand it. I have been able to ask some questions.

I am happy for my keyworker or carer to be approached and interviewed.

I agree that my GP is notified and that he/she may release information about relevant medical history.

I can decide if I want to take part in the research or not and I can stop if I want to and whenever I want to.

Yes I will take part in the research.

| | | |
|----------------------------|-------------|------------------|
| _____ | _____ | _____ |
| Name of participant | Date | Signature |

| | | |
|----------------|-------------|------------------|
| _____ | _____ | _____ |
| Witness | Date | Signature |

Declaration by the investigator:

I confirm that I have provided an information sheet and explained the nature of the procedures to the volunteer and that his/her consent has been given freely and voluntarily.

Signed

participant id number.....

CONSENT FORM

Title of project: **Support and Relationships in Learning Disabilities**

Name of researcher: **Tessa Lippold**

I have read the information sheet dated 7.11.99 and I understand it. I have been able to ask some questions.

I agree that my GP is notified and that he/she may release information about relevant medical history.

I can decide if I want to take part in the research or not and I can stop if I want to and whenever I want to.

Yes I will take part in the research.

| | | |
|----------------------------|-------------|------------------|
| _____ | _____ | _____ |
| Name of participant | Date | Signature |

| | | |
|----------------|-------------|------------------|
| _____ | _____ | _____ |
| Witness | Date | Signature |

Declaration by the investigator:

I confirm that I have provided an information sheet and explained the nature of the procedures to the volunteer and that his/her consent has been given freely and voluntarily.

Signed

participant id number.....

CONSENT FORM

Title of project: **Support and Relationships in Learning Disabilities**

Name of researcher: **Tessa Lippold**

I have read the information sheet dated 7.11.99 and I understand it. I have been able to ask some questions.

I can decide if I want to take part in the research or not and I can stop if I want to and whenever I want to.

Yes I will take part in the research.

| | | |
|----------------------------|-------------|------------------|
| Name of participant | Date | Signature |
|----------------------------|-------------|------------------|

| | | |
|----------------|-------------|------------------|
| Witness | Date | Signature |
|----------------|-------------|------------------|

Declaration by the investigator:

I confirm that I have provided an information sheet and explained the nature of the procedures to the volunteer and that his/her consent has been given freely and voluntarily.

Signed

participant id number.....

Social Support Self Report

Social Support Self Report (SSSR)

(***IF they give a non-personal name, ask: Who do you mean?)

1. Who lives at this address with you? _____
 2. Are you married? _____ [If yes] Spouse's name _____ [If unmarried] Do you have a boyfriend or girlfriend? _____ What is his or her name? _____ Where does s/he live? _____
 3. Is your mother alive? _____ Where does she live? _____
 4. Is your father alive? _____ Where does he live? _____
 5. Do you have any brothers? _____ sisters? _____ aunts? _____ uncles? _____ grandparents? _____ Where do they live? _____
 6. Who do you get along with best? _____
 7. Do you have any friends? _____ Who are they? _____
 8. Who is your best friend? _____ Your second best friend? _____
 9. Where do they live? _____
 10. Do you have roommates? _____ Who are they? _____
 11. Do you have friends at work? _____ Who are they? _____
 12. ^{Is anyone employed to care for you?} (Do you have any staff?) _____ Who are they? _____
 13. Is there any body else important to you? _____
- Thinking about you.....*
 (For each important person identified).. (a lot, sometimes, not at all)
- A. How often do you see or talk to _____ on the phone?
 - B. How often do you talk to _____ about your feelings?
 - C. How much do you like _____?
 - D. How much does _____ help you with your problems?
 - E. How much do you help _____ with his/her problems?

| | family | staff | friends | partner |
|------------|--------|-------|---------|---------|
| A talk | | | | |
| B feelings | | | | |
| C like | | | | |
| D problem | | | | |
| E recip | | | | |

Circles task

LIKERT SCREEN: Now I will ask you lots of questions about things you do with people. For most of these questions, you can say "a lot," "sometimes" or "not at all."

1st check: If I asked you: How often do you go to the picture? what would you say?

2nd check: If I asked you: How often do you drive a torry? What would you say?

3. How often do you have a cup of tea or coffee?

Circles Task

Pretend this is you in the middle (point to the center of the middle circle where it says "ME.") We are going to put down the names of everybody who is important to you in these circles around you. I want you to think of all the people who are important in your life right now.

1. Tell me the people who you feel so close to that it is hard to imagine life without them:

2. Now tell me the people who you don't feel AS close to but who are still very important to you:

3. Now tell me the people who you didn't mention yet but who are close enough and important enough to be in your circle.

*after each name ask:

Who is that? Or Where do you know him or her from?

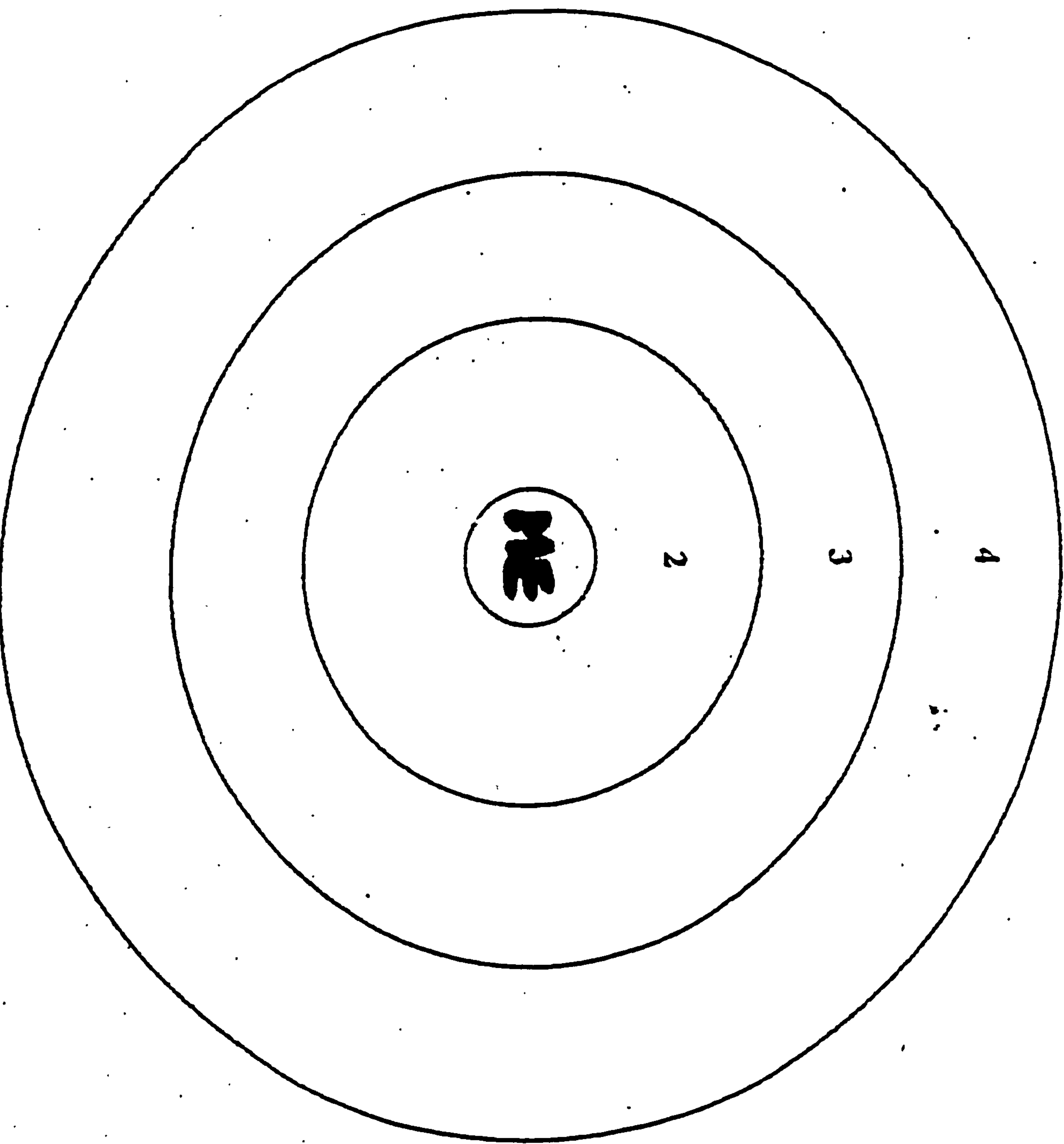
Also ask: Which of these people does _____ know?

IF they give a non-personal name, ask: Who do you mean?

Text cut off in original

SOCIAL NETWORK MAP

ID. _____



Functional Support Interview

Functional support interview

Now I am going to give you descriptions of things people do sometimes for other people. You tell me if there are people who do these things for you. You can name me up to three people for each.

(If they just give one or two names, ask: *Is there anyone else?*)

If they give a non-personal name, ask: *Who do you mean?*)

1. Is there someone you can count on for sympathy and understanding? Like if something bad happened to you and you needed a friend who would understand and help you feel better?

A.

B.

C.

2. Is there someone you can count on for pleasant companionship? Like to do fun things with and keep you company?

A.

B.

C.

3. Is there someone you can count on for help with household or personal tasks? Like if you needed help with cleaning the house or your banking, or writing a letter?

A.

B.

C.

4. Is there someone you can count on for advice if needed? Like if you had a problem, and didn't know what to do about it?

A.

B.

C.

5. Is there someone you know who recognizes special abilities that you have? Like who knows about the things that you are really good at and tells you so?

A.

B.

C.

6. Is there someone who relies on you for their care or part of their care? Like if they need something, or need help or need a friend, do they count on you?

A.

B.

C.

6b. What sorts of things do you do for people? (Probe: Is there anything else?)

Social Circles Questionnaire

SOCIAL CIRCLES QUESTIONNAIRE

Please answer the following questions about the social circle of a person with learning disabilities whom you know well. Social networks are an important part of any person's life. We are interested in the kinds of people who are involved with people who have learning disabilities, and what sorts of things they do together.

Remember, your responses are confidential and anonymous. Please answer questions as completely as you can. If you are uncertain, circle "DK" meaning "I don't know".

If you feel a response requires an explanation, please do so at the end of the questionnaire. We are very interested in your experiences and opinions with regard to social support issues.

Thank you.

Person with learning disability: (please circle correct response)

Gender: male female

Living arrangement: family staffed home supported living
 independent other _____

Level of functioning: mild learning disability moderate learning disability
 other _____

Does the person have a psychiatric diagnosis? NO YES, specify _____

Your relationship to person: mother father sibling residential staff
 other, specify _____

How long have you known this person? _____

Please answer all the following questions about the person's FAMILY, WORKERS, FRIENDS, and BOY/GIRLFRIENDS

1. FAMILY (all family including aunts, cousins and grandparents if they are important)

- | | |
|--|--------------|
| (a) number of family members involved with person | 0 1 2 3 4 DK |
| (b) number of family who phone at least 1/month | 0 1 2 3 4 DK |
| (c) number of family who visit/go out at least 1/month | 0 1 2 3 4 DK |

* If answered "0" to all, skip to WORKERS

- | | |
|--|--------------|
| (d) number of visits/outings per month | 0 1 2 3 4 DK |
| (e) number of phone calls per month | 0 1 2 3 4 DK |

for (f) to (p): 0=never 1=once in a while 2=sometimes
 3=often 4=very often DK=don't know

- | | |
|--|--------------|
| (f) family listens to person's problems | 0 1 2 3 4 DK |
| (g) family helps with practical issues | 0 1 2 3 4 DK |
| (h) family plans special activities/outings | 0 1 2 3 4 DK |
| (i) family shows day to day concern | 0 1 2 3 4 DK |
| (j) family provides warmth/comfort | 0 1 2 3 4 DK |
| (k) person gets nervous before family visits | 0 1 2 3 4 DK |
| (l) person is upset/frustrated after visits | 0 1 2 3 4 DK |
| (m) person phones family | 0 1 2 3 4 DK |
| (n) person listens to family members' problems | 0 1 2 3 4 DK |
| (o) person makes plans to see family | 0 1 2 3 4 DK |
| (p) person provides every day support | 0 1 2 3 4 DK |

2. WORKERS (all staff, residence, day program, case managers, part time)

- | | |
|---|--------------|
| (a) number of workers involved with person | 0 1 2 3 4 DK |
| (b) number of workers who phone at least 1/month | 0 1 2 3 4 DK |
| (c) number of workers who visit/go out at least 1/month | 0 1 2 3 4 DK |

* If answered "0" to all, skip to FRIENDS/ROOMMATES

(d) number of visits/outings per month 0 1 2 3 4 DK

(e) number of phone calls per month 0 1 2 3 4 DK

for (f) to (p): 0=never 1=once in a while 2=sometimes
3=often 4=very often DK=don't know

(f) worker(s) listen to person's problems 0 1 2 3 4 DK

(g) worker(s) help with practical issues 0 1 2 3 4 DK

(h) worker(s) plan special activities/outings 0 1 2 3 4 DK

(i) worker(s) show day to day concern 0 1 2 3 4 DK

(j) worker(s) provide warmth/comfort 0 1 2 3 4 DK

(k) person gets nervous before worker(s) visit 0 1 2 3 4 DK

(l) person is upset/frustrated after visits 0 1 2 3 4 DK

(m) person phones worker(s) 0 1 2 3 4 DK

(n) person listens to worker(s)' problems 0 1 2 3 4 DK

(o) person makes plans to see worker(s) 0 1 2 3 4 DK

(p) person provides every day support 0 1 2 3 4 DK

3. FRIENDS/ROOMMATES (this includes people with and without L. Dis. . . It can include roommates or co-workers, so long as they are people who choose to spend free time together)

(a) number of friends involved with person 0 1 2 3 4 DK

(b) number of friends who phone at least 1/month 0 1 2 3 4 DK

(c) number of friends who visit/go out at least 1/month 0 1 2 3 4 DK

* If answered "0" to all, skip to BOYFRIENDS/GIRLFRIENDS

(d) number of visits/outings per month 0 1 2 3 4 DK

(e) number of phone calls per month 0 1 2 3 4 DK

for (f) to (p): 0=never 1=once in a while 2=sometimes
3=often 4=very often DK=don't know

(f) friend(s) listen to person's problems 0 1 2 3 4 DK

(g) friend(s) help with practical issues 0 1 2 3 4 DK

(h) friend(s) plan special activities/outings 0 1 2 3 4 DK

(i) friend(s) show day to day concern 0 1 2 3 4 DK

| | |
|--|--------------|
| (j) friend(s) provide warmth/comfort | 0 1 2 3 4 DK |
| (k) person gets nervous before friend(s) visit | 0 1 2 3 4 DK |
| (l) person is upset/frustrated after visits | 0 1 2 3 4 DK |
| (m) person phones friend(s) | 0 1 2 3 4 DK |
| (n) person listens to friend(s)' problems | 0 1 2 3 4 DK |
| (o) person makes plans to see friend(s) | 0 1 2 3 4 DK |
| (p) person provides every day support | 0 1 2 3 4 DK |

4. BOY/GIRLFRIENDS (this includes anyone who has a romantic relationship with the person)

| | |
|--|--------------|
| (a) number of b/gfriends involved with person | 0 1 2 3 4 DK |
| (b) number of b/gfriends who phone at least 1/month | 0 1 2 3 4 DK |
| (c) number of b/gfriends who visit/go out at least 1/month | 0 1 2 3 4 DK |

* If answered "0" to all, GO TO COMMENTS SECTION.

| | |
|--|--------------|
| (d) number of visits/outings per month | 0 1 2 3 4 DK |
| (e) number of phone calls per month | 0 1 2 3 4 DK |

for (f) to (p): 0=never 1=once in a while 2=sometimes
 3=often 4=very often DK=don't know

| | |
|---|--------------|
| (f) b/gfriend(s) listen to person's problems | 0 1 2 3 4 DK |
| (g) b/gfriend(s) help with practical issues | 0 1 2 3 4 DK |
| (h) b/gfriend(s) plan special activities/outings | 0 1 2 3 4 DK |
| (i) b/gfriend(s) show day to day concern | 0 1 2 3 4 DK |
| (j) b/gfriend(s) provide warmth/comfort | 0 1 2 3 4 DK |
| (k) person gets nervous before b/gfriend(s) visit | 0 1 2 3 4 DK |
| (l) person is upset/frustrated after visits | 0 1 2 3 4 DK |
| (m) person phones b/gfriend(s) | 0 1 2 3 4 DK |
| (n) person listens to b/gfriend(s)' problems | 0 1 2 3 4 DK |
| (o) person makes plans to see b/gfriend(s) | 0 1 2 3 4 DK |
| (p) person provides every day support | 0 1 2 3 4 DK |

Life Experiences Checklist

Alastair Ager

Scores

Leisure

Relationships

Freedom

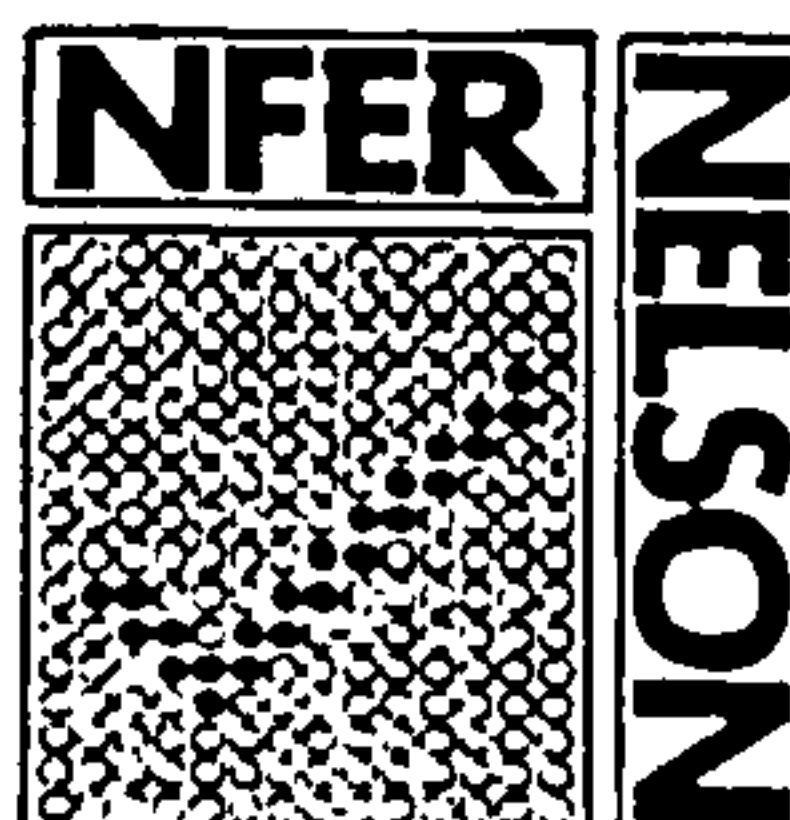
Opportunities

Total

Comments _____

All rights reserved, including translation. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, recording or duplication in any information storage and retrieval system, without permission in writing from the publisher, and may not be photocopied or otherwise reproduced even within the terms of any licence granted by the Copyright Licensing Agency Ltd.

Code 4250 01 4



Please tick the statements which apply to you or — if filling it in on behalf of someone else — the above-named person. No one is likely to score 'full marks'. Just tick the statements that genuinely apply.

Home

| | |
|---|--------------------------|
| My home has more rooms (counting living-rooms and bedrooms) than people | <input type="checkbox"/> |
| My home is well decorated (e.g. it does not require a lot of repapering, painting etc.) | <input type="checkbox"/> |
| My home is carpeted and has comfortable furniture | <input type="checkbox"/> |
| My home has a garden | <input type="checkbox"/> |
| I have never been attacked by someone when at home | <input type="checkbox"/> |
| I have never had anything of mine stolen from home | <input type="checkbox"/> |
| I use a telephone at home at least once a week | <input type="checkbox"/> |
| My home has central heating | <input type="checkbox"/> |
| Visitors have sometimes said how nice they think my home is | <input type="checkbox"/> |
| I have my own room (or share with my partner only) | <input type="checkbox"/> |
| Subsection score | <input type="checkbox"/> |

Comments

Leisure

| | |
|---|--------------------------|
| I visit friends or relatives for a meal at least once a month | <input type="checkbox"/> |
| I go to a cafe or restaurant for a meal at least once a month | <input type="checkbox"/> |
| I do some sport at least once a month | <input type="checkbox"/> |
| I go to a local club, class or meeting at least once a month | <input type="checkbox"/> |
| I go to the cinema or theatre at least once a month | <input type="checkbox"/> |
| I go out to meet friends or relatives (e.g. at the pub or in someone's home) at least once a week | <input type="checkbox"/> |
| I go away on holiday for at least two weeks each year | <input type="checkbox"/> |
| I go to church (or other place of worship) at least once a month | <input type="checkbox"/> |
| I have a hobby or interest (e.g. photography or collecting) | <input type="checkbox"/> |
| There is lots for me to do at home (e.g. play records, watch videos, play games, read books etc.) | <input type="checkbox"/> |
| Subsection score | <input type="checkbox"/> |

Relationships

| | |
|---|--------------------------|
| I have several close friends | <input type="checkbox"/> |
| I feel loved and accepted by those who live with me | <input type="checkbox"/> |
| I am called by my first name by those who live with me | <input type="checkbox"/> |
| Some people address me formally (that is, call me Mr, Mrs, or Ms _____) | <input type="checkbox"/> |
| I am married (or have a steady partner) | <input type="checkbox"/> |
| I have friends to stay with me at home at least once a year | <input type="checkbox"/> |
| When I am sad there are people who listen to me and help me | <input type="checkbox"/> |
| There are both men and women living in my home | <input type="checkbox"/> |
| I stay overnight with friends at least once a year | <input type="checkbox"/> |
| I get on well with my family | <input type="checkbox"/> |
| Subsection score | <input type="checkbox"/> |

Freedom

| | |
|---|--------------------------|
| I can spend time by myself (in privacy) when I want to | <input type="checkbox"/> |
| I chose (or helped choose) how my home is decorated | <input type="checkbox"/> |
| I myself chose to live in my present house | <input type="checkbox"/> |
| I have a bank or post office account from which I can withdraw money | <input type="checkbox"/> |
| Meal times are changed to fit in with my plans | <input type="checkbox"/> |
| I choose for myself what I do in my spare time | <input type="checkbox"/> |
| I have a vote in elections | <input type="checkbox"/> |
| I have my own personal possessions (which others may use if I choose) | <input type="checkbox"/> |
| I earn some money (other than benefit or pension) | <input type="checkbox"/> |
| I choose my own clothes | <input type="checkbox"/> |
| Subsection score | <input type="checkbox"/> |

Opportunities

Local shops are a short walk away

I travel by car or public transport at least once a week

When I am sick I can get to see a doctor easily (doctor visits or is just walking distance away)

I cook meals (perhaps with help) at least once a week

I can make myself drinks or snacks whenever I want to

I do some jobs in the home (e.g. washing up, cleaning)

I have a pet

I enjoy what I do during the day

What I do during the day is of help or value to others

I am being taught some new skill

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Subsection score

| |
|----------------------|
| <input type="text"/> |
|----------------------|

Comments

Semi- structured interview schedule

Interview Schedule

(Obtain consent to be audiotaped and remind about confidentiality)

Thank you for agreeing to see me again. You have already answered lots of questions about your family and friends and people who are important in your life. Now I'd like to give you a chance to talk some more about relationships and what it means to you to feel close to someone.

To start with I'd like to remind you of some of the things you told me when I saw you the first time.

(refer to circles, pick out some of the key people mentioned and encourage comment)

The people who are closest in your circles are....

You mentioned some friends here.

1. What do you think it means to have a friend?
2. If you had to tell someone what friendship means what would you say?
3. You told me you had/didn't have a best friend. What's different about best friends?
4. What about boy/girlfriends? What's different about a boy/girlfriend and a friend?
5. Is it important to have a boy or girlfriend? Why?
6. What do you think it means when people talk about intimacy or intimate relationships? (give examples/definition if necessary).
7. Have you ever had any very close relationships?
8. How do you think people feel when they don't have any close relationships? How would it make you feel?
9. What about other kinds of friendship? Can you be friends with staff?
10. Is there anything else that's important about relationships? Anything else you'd like to say?

(Thank again, remind about confidentiality)

Sample of transcript

He was, he was.

So you've mentioned some friends here. What do you think it means to have a friend?

trust

If you can trust them.

Definition of
a friend

So a friend is someone you can trust.

ambivalence/
contradiction

Yes. Sometimes I've got friends I can't trust. That's difficult because I've got friends I can trust and I've got friends I can't trust.

Yeah.

You know sometimes they really upset me and I don't like it and I can't trust them.

Right. So tell me what you think it means to have a friend.

^{likable}
/ They're very kind / they help you when you're feeling a bit down, umm, they help me when I'm feeling a bit miserable, not happy, they come and talk to me sometimes. Sometimes they ask me if I want a drink with them.

What it means
to have
a friend

emotional
support
practical aspects

Yeah.

And you know we talk about things how we feel.

Right. So a friend is someone who is kind, helps you when you're down and someone that you can share...

Yeah

...things with, and talk to about things with. So if you had to tell someone what friendship means what would you say?

lasting name
of
friendship

It's a, is it a friend? or a boyfriend? Friendship means you keep it.

Definition
of
friendship

Right, so there's something about a friendship lasting. Is that right?

lasting nature
of relationship

Yeah. I've been out with D for five years, I kept him.

D's a friend?

No, boyfriend.

D's a boyfriend, right. So what's different between a friend and a boyfriend do you think?

Distinction
between
friend and
boyfriend.

practical
support

Friends talk don't they. Friends talk. Like boyfriends -
like they love you.

Yeah.

It's exactly the same.

Okay so it's the same only they love you.

Yeah.

So that's a bit different, that they love you. Is having a boyfriend a closer relationship?

Yeah, yeah.

Is it important to have a boyfriend?

Umm, yes I think it does.

Why would you say it's important to have a boyfriend?

emotional
support
practical
support

'cause they make you happy. Makes you happy to do things with them, go out with them or go round their house at weekends. That's the kind of relationship I've got. A very good one.

Importance
of having
a boyfriend

Is it a very close relationship?

Yeah it is. Yeah.

And you've got a boyfriend at the moment have you?

Yes, that's D.

How often do you see D?

When I go out with B on Wednesdays if I not at college I go and see D. I see D, if I've got no college I go out with B. Then I see D.

Have you had lots of boyfriends?

I've had loads! I didn't not like.

What makes a good boyfriend?

You don't want, you don't, you don't have to, don't have to force you to do things with them you don't want to do with them.

Right. What kinds of things do boyfriends sometimes force you to do?

I'm not saying that.. Um, not very nice thing to say. Might go in their bedrooms, but I said no, cause I can't even trust them.

You can't trust them. So if that happens you'd say you don't want to be their girlfriend any more.

No, no.

Is that right?

Yeah I'll say if it happens again I don't ever want to see you again.

Right.

I do mean it this time. I stand up on my two feet and tell them. J says that I'm getting more clever now to do, to tell them why.

To tell them what you think and how you feel.

Yeah.

What about intimate relationships? What do you think it means to have intimate relationships?

(hesitation)
negative aspects
of having
boyfriends

hints at being
made to have
sex
lack of trust

standing up
for self

having
confidence to
assert self.

implied sexual
pressure

implied
sexual
pressure

Asserting self

I don't know what that means.

That means when you're very, very close to someone.

example of
close
relationship

I'm close to my foster mum. I'm close to her. 'cause I'm in her care.

Yeah.

And me and her are like that [gestured with her hands, bringing both forefingers together].

knowledge of
v. close
relationship

Yes, and you've been with her a long time haven't you.

confirmation

A very long time. I'm like that with her [gestured again], more close.

So when you are close like that to someone what does that mean?

reciprocity in
relationship

It means you really like them and you care about them, you really care, well I do. She brought me up like her own kid.

Yes.

Like one of her own kids, and she buys me stuff and that's very good you know. That means I'm close to her, you know. I'm close to my sister as well, she's more close to me as well, you know, she asks me to go all about with her and I say yes. I mean, 'cause my sister and me are really like kind of twins, twin sister.

example of
close
relationship

You're like twin sisters are you.

And she's always asking to go out with me and I say yes and I do. So, yeah.

And do you see much of your sister?

She lives with me.

So you do see a lot of her then.

Yes.

How do you think it makes you feel when you don't have anybody to be very close to?

expression of
sadness
emotional
consequences
ambivalence/
contradiction

It'd make me feel sad. Very sad. It makes me feel very sad if I don't have nobody and I'd feel very sad, you know, on my own. Ner - might have a ner breakdown sometimes on my own when I get upset, in tears and all kind of something like that. And but I, 'cause I think other people don't care about me, but they do. Well that's to say they don't mean it.

Impact of
lack of
close
relationship

Yes.

'Cause I'm sorry to say that, 'cause I don't mean it like that, but at least they say sorry and don't mean to say it.

You told me last time that you'd had some bad relationships, didn't you.

negative
aspect of
relationship

Yeah. I had one from J at first. He's very nasty and trouble to me, getting to me. And there was D as well.

Yes.

It was them as well. Not all relationships with boys.

So not all relationships with boys are like that.

standing up
for self in
face of adversity

No. I found it, I found like no I wouldn't put up with this, that's it, you're gone, out of my sight, I say it right in their face. I stand up on my own two feet and tell them I want to be on my own. So that was it.

asserting self

And that was because they were making you do things you didn't want to do.

seeking support
& advice from
staff

Yeah. And I told J. She said you don't have to do things you don't want to. It's not up to them, so it's up to you to decide.

supportive
role of
staff

That's right.

Outline transcript

Outline transcript 4, participant 26 (male)

1. What it means to have a friend

- Makes you happy
- You can play games with them
- You can go out with people
- You can see [name of friend] and you can go up there
- He's my really good mate, my really good mate. And he knows when I come in because he always smiles at me, but he can't talk
- It's just nice to talk to him

2. Definition of friendship

- We all got friends and you're happy to talk to them
- A best friend and a good friend are both the same

3. Difference between friend and girlfriend

- I haven't got one
- I want to be her friend but not a real friend, a real boyfriend, going out together
- You make friends talking to a person but a relationship, it goes more
- Like you can get married or you can get friends

4. Is it important to have a girlfriend?

- It's nice , it's nice to talk to cause you can't talk to yourself
- It's nicer if you're happy with that, that person

5. What makes a good girlfriend?

- I used to get on with [name of previous girlfriend] a lot
- [name of previous girlfriend] helped me get in the car

6. What doesn't make a good girlfriend?

- I went to L in France and when I came back she was with someone else

7. Coping with problems in relationships

- I really don't want to talk about it [previous relationship]
- I don't get on with my parents

- Once I booked a day to go and see my friend...and no-one told [name of friend] I'm here. I mean I was really angry
- Because one....I don't like being bathed...and two, they [parents] won't let me go out
- She [stepmother] never, ever tell me the truth where they live
- I like to be friends but with this person [ex-girlfriend] it's not easy

8. Consequences of problems in relationship with girlfriend

- I was really crying because that person let me down and it's not nice
- 'cause I been let down before and I don't want to be let down again and again and again
- they let me down
- I will never get married

9. Understanding of intimacy and intimate relationships

- Never heard of it
- It's nice, but I won't have one

10. How it feels not to have someone to be close to

- Down. And upset, angry

11. Can you have close relationships with staff?

- That's hard. Could I be friends to staff at my home? They might be married, there's that side, or their husband might come in
- There's one person who I hate and that's [name of member of staff] he looks down on you
- That's hard 'cause you got to be friends but if, right, they were married, what happens, there'd be a row